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The clinical care of patients with lung cancer identifying and supporting those with unmet care needs

Buchanan, Deans

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Deans Buchanan

2010

University of Dundee

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The Clinical Care of Patients with Lung Cancer

Identifying and Supporting Those with Unmet Care Needs

Deans Buchanan

Medical Doctorate

University of Dundee

August 2010

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I certify that I am the author of this thesis. Unless stated otherwise, I have consulted all cited references. It has been composed by the author and has not been previously submitted for examination which has led to the award of a degree.

Signature of Author: _____ Date:_____

Abstract

Introduction

Lung cancer has developed from a rare condition into the leading cause of cancer-related death in the United Kingdom. Lung cancer patients face a disease with a high symptom burden, increased psychosocial needs and a high mortality. Supportive care needs are often relevant from diagnosis. Despite this, there are no clear follow-up structures for lung cancer patients that address both cancer management and supportive care. The aims of this study were to evaluate supportive care needs, assess predictors of such needs and identify factors which could aid service provision within Stobhill lung cancer services.

Methods

Supportive care needs were measured using an adapted Palliative Outcome Scale (POS), incorporated within a larger questionnaire. All lung cancer patients attending the clinic could complete this questionnaire. Respiratory symptoms, performance status, service usage, preferences and satisfaction were also assessed. Data were stratified to allow evaluation of three clinical groupings: all patients, newly diagnosed patients and patients in the last three months of life. Analyses were phased: descriptive analyses, univariate tests of association and multivariate regression.

Results

Three hundred and fifty three lung cancer patients completed questionnaires. The high symptom burden in lung cancer was confirmed. Anxiety, pain and dyspnoea were identified as the key issues. Poor performance status was identified to be an independent predictor of increased POS score, increased anxiety, increased pain and increased dyspnoea. There was no independent relationship between POS and survival. Although the majority of patients were satisfied with the care received, there was uncertainty regarding who was in charge of care and some disparity in preferred structure for follow-up.

Conclusions

Despite recent advances in lung cancer management, improvements are still required to address unmet supportive care needs of patients. Particular attention should be given to those with poorer performance status to effectively identify and meet such needs.

Abbreviations

ACCP	American College of Chest Physicians
ACR	American College of Radiology
AQEL	Assessment of quality of life at the end of life
ASCO	American Society of Clinical Oncology
BTS	British Thoracic Society
CCM	Cancer Care Monitor
CI	Confidence interval
CLC	Clinico-radiological lung cancer
COPD	Chronic Obstructive Pulmonary Disease
CRP	C-Reactive protein
CT	Computer tomography
CXR	Chest x-ray
df	Degrees of freedom
EBUS	Endoscopic bronchial ultrasound
ECOG	Eastern Cooperative Oncology Group
EORTC	European Organisation for Research and Treatment of Cancer
EORTC QLQ-C30	EORTC Quality of Life Score
ESMO	European Society for Medical Oncology
FDA	Food and Drug Administration
GP	General practitioner
GPS	Glasgow Prognostic Score
HADS	Hospital Anxiety and Depression Score
HRQOL	Health-related quality of life
IHA	Initial Health Assessment
IL-6	Interleukin 6
UICC	International Union Against Cancer
KPS	Karnofsky Performance Status
LCQ	Lung Cancer Clinic Questionnaire
LDH	Lactate dehydrogenase
MDASI	MD Anderson Symptom Inventory
MDT	Multidisciplinary team
MND	Motor neurone disease
MPQ	McGill Pain Questionnaire
MRI	Magnetic resonance imaging

NICE	National Institute for Health and Clinical Excellence
NRES	National Research and Ethics Committee
NSCLC	Non-small cell lung cancer
PCI	Prophylactic cranial irradiation
PET	Positron emission tomography
POS	Palliative Outcome Scale
PPV	Positive predictive value
PRO	Patient-reported outcome
PROM	Patient-reported outcome measure
PS	Performance status
PSQ	Patient satisfaction questionnaire
Q1	Questionnaire 1
QF	Final questionnaire
QOL	Quality of life
RCT	Randomised controlled trial
SCLC	Small cell lung cancer
SCNS	Supportive care needs survey
SD	Standard deviation
SDS	Symptom Distress Scale
SE	Standard error
SES	Symptom Experience Scale
SF-36	Short Form 36, Health Status Survey
SIGN	Scottish Intercollegiate Guideline Network
SIS	Stobhill Information Services
SPARC	Sheffield Profile for Assessment and Referral to Palliative Care
SPLC	Second primary lung cancer
SVCO	Superior vena caval obstruction
TBNA	Transbronchial node aspiration
TNM	Tumour, node and metastases
UK	United Kingdom
USA	United States of America
VATS	Video assisted thoracoscopy
WHO	World Health Organisation
$\bar{x}$	Mean
X^2	Chi squared

Publications and Presentations

Publications

Perceptions of anxiety in lung cancer patients and their support network. Buchanan D, Milroy R, Baker L, Thompson AM and Levack P. *Supportive Care in Cancer* 2010:18(1):29-36.

Oral Presentations

Respiratory symptoms and palliative care needs in lung cancer patients. Buchanan D, Milroy R, Baker L, Thompson AM and Levack P. EAPC, Trondheim, Norway, 2008. Abstract published in *Palliative Medicine* 2008;22(4):503.

Perceptions of anxiety in lung cancer patients and their support network. Buchanan D, Milroy R, Baker L, Thompson AM, Levack P. Palliative Care Congress, Glasgow, 2008.

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Respiratory symptoms and palliative care needs in lung cancer patients. Buchanan D, Milroy R, Baker L, Thompson AM, and Levack P. NCRI conference, Birmingham, 2007.

Respiratory symptoms in lung cancer patients, prognostic factors and palliative care needs. Buchanan D, Milroy R, Baker L, Thompson AM and Levack P. Scottish Society of Physicians, Peebles 2007.

1 Introduction

Lung cancer patients face a disease with high symptom burden,[1] increased psychosocial distress[2] and poor survival.[3] Lung cancer stands out from other cancers in both the symptom burden and distress it causes.[4-6] Lung cancer patients also face difficult decisions throughout the course of their illness regarding treatment choices.[7-9] Despite this, little is known about patients' preferences and priorities for care.[10] Lung cancer services are not meeting the needs of all patients; in particular, the psychological and social needs of patients often remain unmet.[11-14] The management of lung cancer includes investigation, diagnosis, treatment, supportive care and follow-up.[10] While there is growing evidence and options for most stages of management, there continues to be a lack of evidence regarding follow-up.[10] It is within the follow-up phase that supportive care issues could most readily be addressed if they are identified.

This study aims to evaluate the prevalence of supportive care needs within Stobhill Hospital's lung cancer multidisciplinary clinic, assess predictors of overall supportive care needs as measured by the Palliative Outcome Scale, and evaluate the key issues reported by patients. It will consider patients' perceptions of and preferences for follow-up care and their satisfaction with the current service. It is hoped that increased understanding of these issues may allow service improvements in the future.

A conceptual outline of the current study is presented below (Figure 1):

- Understand lung cancer
    - History and epidemiology (Sections 1.1-1.3)
    - Management (Section 1.4)
    - Why is supportive care of importance in lung cancer? (Section 1.5.3)
- Identify unmet need
    - Prevalence of symptoms in lung cancer (Section 5)
    - Descriptive evaluation of supportive care needs in patients attending the Stobhill lung cancer clinic (Section 6)
    - Key supportive care needs and their predictors (Sections 7 and 9-11)
- Understand the urgency
    - Survival and prognostication (Sections 1.4.5 and 8)
    - Evaluation of survival within the lung cancer clinic (Section 8)
    - Predictors of poorer survival (Section 8)
- Evaluate service and preferences
    - What is the evidence for current models of follow-up (Section 4)
    - Evaluation of patients' views of the current service use (Section 6)
    - Identify patients' views for future service provision (Section 6)
    - Integration of supportive care into lung cancer management (Section 1.4)

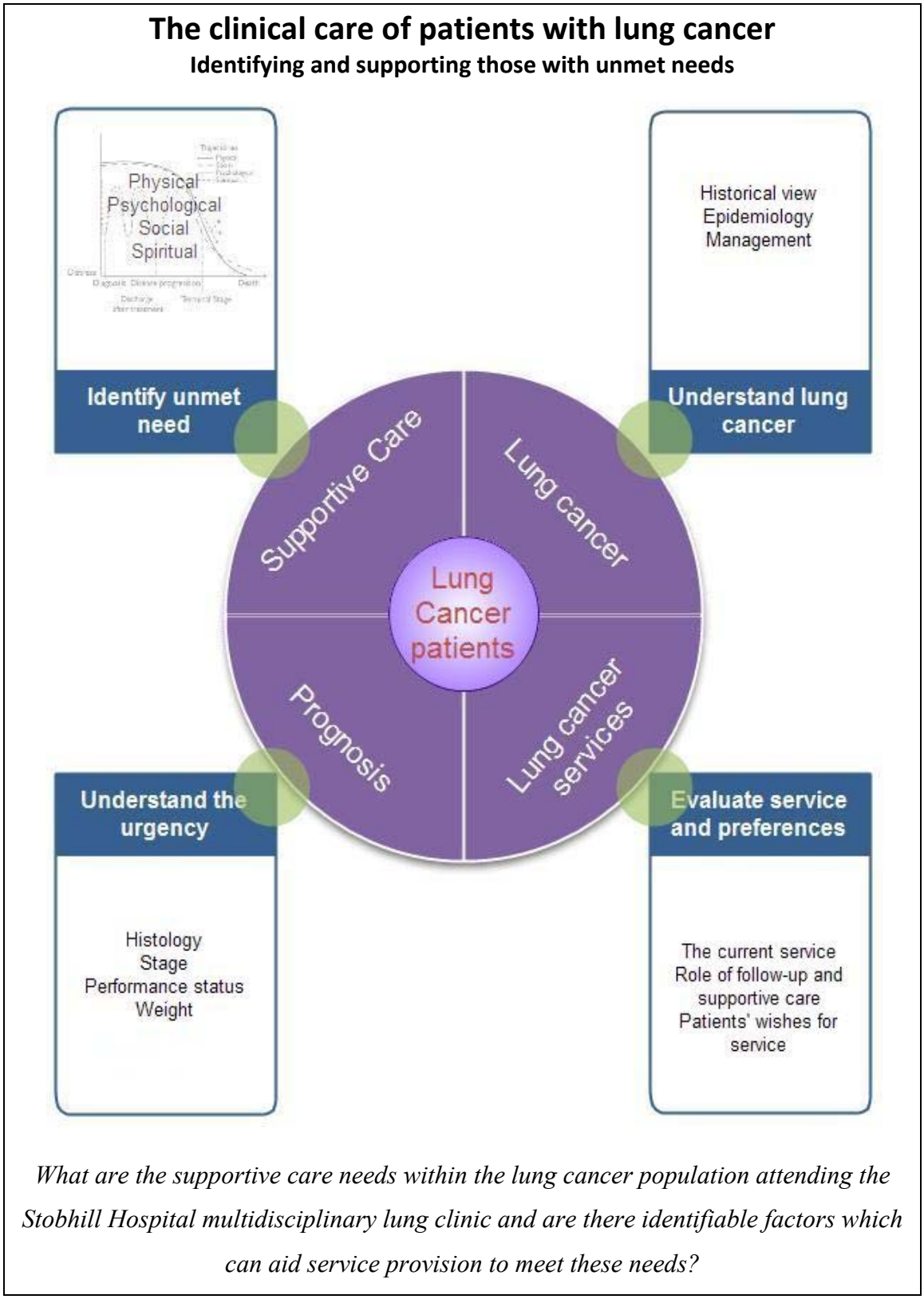


Figure 1: A conceptual outline of the current study.

The introduction section outlines the history and epidemiology of lung cancer. It further describes management of lung cancer including prevention, diagnosis, staging, treatment, prognostication, supportive care and follow-up. The concept of symptom distress (or symptom burden) is introduced and the supportive care needs and symptoms of lung cancer are outlined. Finally, the background to the project is summarised and the aims presented.

1.1 Historical Perspective of Lung Cancer

Lung cancer is now the leading cause of cancer-related death worldwide,[15] in contrast to one hundred years ago when lung cancer was virtually non-existent. In 1849, John Hughes Bennet, Professor of Pathology, University of Edinburgh, wrote 'This is the only case of cancer of the lung which I have ever met with; so that I presume that the disease rarely attacks this organ in Scotland.'[16] In 1912, Adler asked 'Is it worthwhile to write a monograph on the subject of primary malignant tumours of the lung?' At this time Dr. Issac Adler could verify only 374 cases within the world literature and lung cancer was a reportable disease.[17-19] He notes in his introduction that '...even now the overwhelming majority of medical practitioners rarely, if ever, think of a diagnosis of tumour of the lungs.'[18]

From these first few cases, the incidence of lung cancer increased throughout the 20th century. In 1878, lung cancer represented only 1% of cancers found at post-mortem in the Institute of Pathology of the University of Dresden, Germany. By 1918, this had increased to almost 10% and again to 14% in 1927.[20]

In 1927, surgeon Alton Ochsner described the increase in lung cancer he was seeing as 'an epidemic'. He contrasted this to his time as a medical student witnessing a lung cancer patient's post-mortem in which he was told the condition was so rare he may never see another case.[21]

The most significant development in the last century in tackling this new epidemic was the recognition that smoking was the causal agent. This fact is now accepted but initially was a matter of great controversy.[22] A variety of causative factors were investigated, including hereditary diatheses, industrial air pollution, gas works, wartime gas exposure, benzene, coal fires, road tars or petrol exposure and the flu pandemic of

1918.[20, 23] The 10% of patients who develop lung cancer but have never smoked are the subject of ongoing debate.[24]

Cigarette smoking was popularised in western cultures at the end of the 19th century. Initially, cigarettes were hand rolled and, therefore, expensive. In 1876, a prize was offered to build a machine to speed up production; James Albert Bonsack developed a machine capable of producing 70,000 cigarettes in ten hours. Despite offering the prize Allen and Ginter did not use the machine, fearing production would outstrip demand. James Buchanan Duke acquired two machines and developed his own business, becoming president of the American Tobacco Company in 1889. World War I helped spread the use and popularity of cigarettes. General John J. Black reportedly stated, 'You ask me what is needed to win this war. I answer tobacco as much as bullets.'[19, 20]

The link between smoking and lung cancer began to be suspected in the 1930's by clinicians noting that this new disease often occurred in smokers. In 1950, Wynder and Graham published *Tobacco as a possible aetiological factor in bronchogenic carcinoma*,[25] and Sir Richard Doll and Austin Hill published a preliminary study in the British Medical Journal confirming that lung cancer was associated with smoking.[26] Doll and Hill went on to study 40,000 British doctors and found that the death rate amongst smokers from lung cancer was 20 times greater than the rate in non-smokers.[27]

These articles were published in a climate in which doctors were avid smokers and advocates of cigarettes through advertising. Claims that smoking was safe were accepted. However, in 1964 the US Surgeon General stated that smoking was 'harmful to health' and advised stopping or avoiding cigarette smoking.[20] Until this report, cigarette use had been increasing but, after publication, it appeared that there was acceptance that smoking was hazardous. In the developed world, smoking rates have since declined with the associated decrease in lung cancer rates lagging approximately 20 years behind.[19] Cigarette smoking continues to rise in the developing world (countries with low or middle incomes). By 1995, 82% of the world's 1.1 billion smokers lived in developing countries.[28]

Over the last one hundred years, lung cancer has developed from a rare condition to a major illness worldwide. The condition about which Adler posed the question 'Is it worthwhile to write a monograph?' is now the most common cancer in terms of

incidence (12.3% of world cancers) and mortality (17.8% of world cancer-related deaths). The condition John Hughes Bennet asserted rarely attacks in Scotland is now the lead cause of cancer-related death in Scotland.

1.2 Epidemiology of Lung Cancer

Estimates of the burden of lung cancer are in terms of incidence, prevalence and mortality. Incidence (or rate of new cases) is defined as 'the number of new cases occurring expressed as an absolute number of cases per year or as a rate per 100,000 people per year.'[15] Prevalence is the number of people alive with the cancer at any given time, including those newly diagnosed and those surviving with the cancer.[15] Mortality rates are the product of the incidence and the fatality of any cancer and, therefore, measure the average risk to the population of dying from that cancer.[15]

The changing landscape of lung cancer across geographical areas, gender, age and socioeconomic divisions over the last 100 years is complex. Around 80-95% of lung cancer is attributable to smoking cigarettes, and the dynamic interplay between smoking prevalence, population growth and altering age demographics accounts for most of the changing patterns of incidence and mortality worldwide. There may be a modest contribution from other factors such as exposure to asbestos or radon, as well as air pollution or diet.[29]

1.2.1 Lung Cancer Worldwide

Lung cancer has been the commonest cancer worldwide since 1985.[30] It is estimated that in the year 2000 there were 10.1 million new cases of cancer, 6.2 million cancer-related deaths and 22 million people living with cancer in the year 2000. Of the worldwide cancer burden, lung cancer is the most common in terms of incidence (1.2 million or 12.3% new cases) and cancer-related deaths (1.1 million or 17.8% of cancer deaths) but lower prevalence (7.9%) than other major cancers[15] (Figure 2).

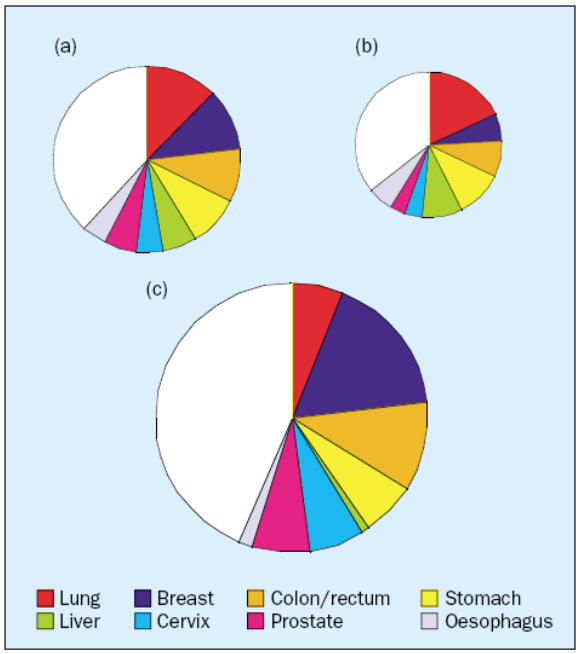


Figure 2: Worldwide incidence (a), mortality (b) and prevalence (c) for major cancers. Reprinted from *The Lancet Oncology*, Copyright 2001, with permission from Elsevier.

This global burden has increased steadily, and these figures compare with 1985 when it was estimated that lung cancer deaths totalled 921,000 worldwide.[19] Currently the highest incidences of lung cancer are seen in Europe and North America.[29] with around 52% of cases occurring within the developed world.[15] However, there are likely to be underestimates of lung cancer in countries where health care is not readily available, as many people are undiagnosed or unreported.

Worldwide, lung cancer is more common in males, with an incidence of 34.9 per 100,000 men compared to 11.1 per 100,000 women.[15] There has been an overall upward trend (by 51%) in number of cases in both genders since 1985; however, the increase has been smaller in men (44%) compared to women (76%). The increase within the male population is accounted for by population growth and aging; age standardised incidence rates in males have decreased slightly over this time period (-3.3%).[30] In women, age standardised incidence rates have increased by 22%. However, lung cancer continues to remain greater in men, in terms of incidence and mortality, throughout the world (Table 1).

		Men	Women	Total
Worldwide[30] *(2003)*	Incidence	35.5 (965,241)	12.1 (386,891)	20 (1.35 million)
	Mortality	27.1 (848,132)	10.7 (330,786)	19.5 (1.17 million)
USA[31] *(2004)*	Incidence	89.9 (114,690)	55.2 (100,330)	68.1 (215,020)
	Mortality	73.4 (90,810)	41.1 (71,030)	53.8 (161,840)
Europe[29, 32] *(2000)*	Incidence	82.5 (303,000)	23.9 (72,000)	52.5 (375,000)
	Mortality	77 (280,000)	22.3 (67,000)	48.7 (347,000)
UK[33] *(2004)*	Incidence	76.9 (22,495)	51.8(15,818)	64.1 (38,313)
	Mortality	66.2 (19,457)	45.7 (14,008)	55.8 (33,465)
Scotland[33] *(2004)*	Incidence	102.8 (2,506)	82.2 (2,160)	92.1 (4,666)
	Mortality	89.9 (2,195)	69 (1,814)	79.1 (4,009)

(Incidence and mortality recorded as crude rates per 100,000 persons (number of cases))

Table 1: Incidence and mortality rates of lung cancer collated from sources.

1.2.2 Lung Cancer in Europe

Within the European Union, the incidence of lung cancer is estimated as 52.5 persons per 100,000 per year with mortality being 48 deaths per 100,000 per year.[32] The incidence of lung cancer in Europe follows the previous patterns of smoking prevalence in each area of Europe.[34] In European men the highest incidence and mortality rates for lung cancer are observed in Eastern Europe with lower rates in Northern Europe. In females there is high incidence and mortality in Northern Europe.[29] Survival from lung cancer is highest in France, Germany, the Netherlands and Switzerland; survival is lowest in Denmark, Poland, United Kingdom (UK) and Scotland.[29]

1.2.3 Lung Cancer in the United Kingdom

In the UK in the 1990's, lung cancer accounted for one in six diagnoses of cancer, one quarter of deaths from cancer and 5% of all deaths.[35] Greater Glasgow has the highest incidence rates of lung cancer in both males and females within the UK.[36] The prognosis for lung cancer patients remains poor, with little improvement in survival over the last 25 years.[19] In the UK, survival at one year for men and women diagnosed with lung cancer is around 25.4% and 27.5%, respectively, and five year survival is 7% and 8%, respectively.[36]

Within the United Kingdom and Ireland:

- 5% of all deaths result from lung cancer;[35]
- lung cancer accounts for one in four of all cancer-related deaths;[33]
- in the 1990's, 37,700 people died from lung cancer each year.[35]

In patients diagnosed with lung cancer:

- 50% die within the first four to six months;[37]
- around 70% die within one year;[37]
- more than 90% will have died within five years.[37]

1.2.4 Lung Cancer in Scotland and Glasgow

Scotland has the highest prevalence of smoking in the UK (28%).[35] Out of a Scottish population of 5,144,200,[38] over 4500 people are diagnosed each year with lung cancer.[36] In Scotland, lung cancer is the leading cause of cancer death in both males and females,[39] and Scotland has the highest incidence of lung cancer within the UK (34% higher in men and 48% higher in females than the UK average);[35] see Figure 3. In Scotland, the incidence of lung cancer in men has fallen over the last 30 years, but the incidence in females has been rising.[40] Although squamous cell carcinoma remains the predominate histological type of lung cancer, rates of adenocarcinoma have been increasing over the same time period.[40] Median survival from lung cancer in Scotland has been reported as 3.6 months,[41, 42] 5.2 months,[43] 6 months,[44] and 9.1 months[45] dependent on area of Scotland and patient selection.

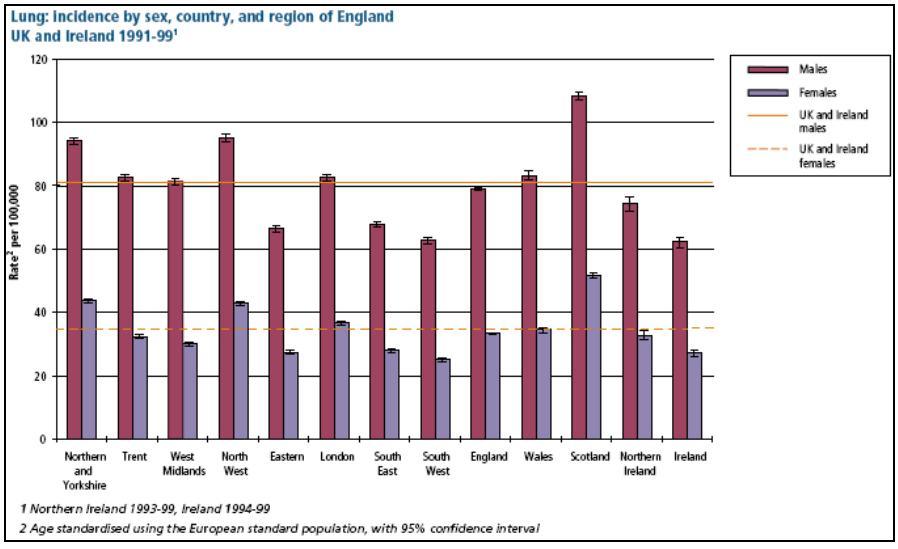


Figure 3: UK lung cancer incidence by gender , country and region.[35] Reproduced from *Cancer Atlas 1991-2000* with permission of the Controller Office of Public Sector Information.

Scotland has a higher mortality rate than the UK average in both males and females[35] (Figure 3).

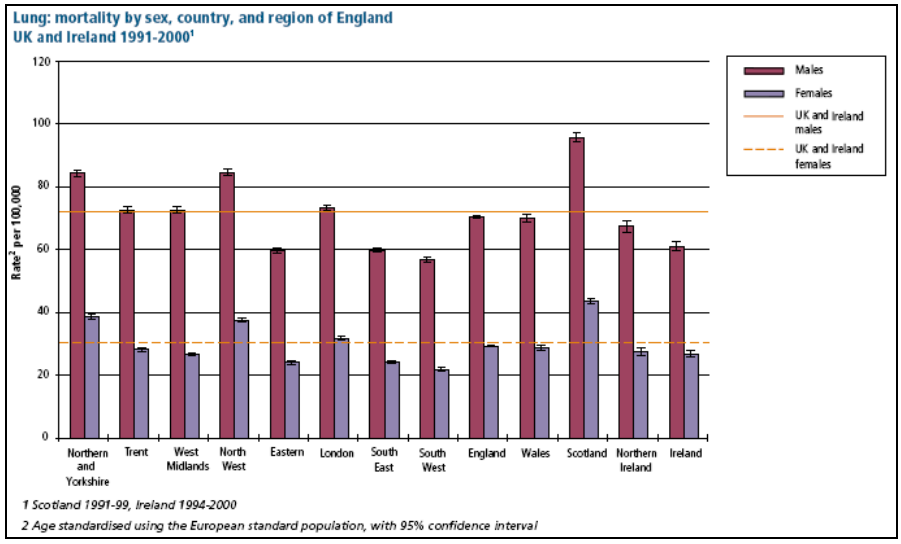


Figure 4: UK lung cancer mortality by gender, country and region.[35] Reproduced from Cancer Atlas 1991-2000 with permission of the Controller Office of Public Sector Information.

Greater Glasgow Health Board has the highest incidence of and mortality from (57% higher than the Scottish average) lung cancer in Scotland.[35]

	Population	Male deaths from lung cancer	Female deaths from lung cancer	Total all cause deaths	Total deaths from lung cancer
Scotland	5,144,200	2239	1876	55,986	4115
Greater Glasgow & Clyde Health Board	621,466	613	559	13,704	1132
Glasgow City	581,940	356	320	7002	676

Table 2: Population, all cause deaths and lung cancer deaths in Scotland. Data collated from the General Register Office for Scotland.[46]

Stobhill Hospital is within the Glasgow City area and within Greater Glasgow and Clyde Health Board. Out of the Glasgow City population of 581,940[38] (11% of Scottish population) in 2007, 676 people died from lung cancer (16.4% of lung cancer deaths in Scotland). In the Greater Glasgow and Clyde Health Board catchment area, deaths from lung cancer numbered 1132 in 2007 (27.5% of Scottish lung cancer deaths). Greater Glasgow and Clyde Health Board cares for over a quarter of patients who die from lung cancer each year in Scotland.[46] More than half of these patients live in the Glasgow City area.[46] As such, this evaluation was conducted within an area where the population has a high risk of developing lung cancer and an extremely poor prognosis if diagnosed with lung cancer.

1.2.5 Deprivation and Lung Cancer

Deprivation is a concept closely related to but not the same as poverty. Measures of deprivation consider material, social or multi-factorial deprivation (income, housing, benefits, employment and material factors). The Carstairs and Morris deprivation index considers material deprivation based on four indicators derived from the 1981[47] Scottish population census and updated in 1991.[48, 49]

- **Overcrowding**: the proportion of all persons living in private households with a density of more than one person per room.
- **Male unemployment**: the proportion of economically active males who are seeking work.
- **Social Class 4 or 5**: the proportion of all persons in private households with head of household in social class 4 or 5
- **Car ownership**: the proportion of all persons in private households with no car

Increased incidence of lung cancer has been associated with deprivation.[50] There may also be a predominance of non-adenocarcinoma lung cancers in deprived populations.[50] In addition, there is a small but significant difference in survival between affluent patients with lung cancer and those who are more deprived.[51, 52] Lower socioeconomic status may also have an influence on quality of life in lung cancer patients.[53]

1.3 Types of Lung Cancer

The term 'lung cancer' refers to a number of different pathological entities rather than a single pathology. Marchesani was one of the first people to propose a histological based classification system for lung cancer.[54] The World Health Organisation (WHO) classification is still based on the four histological subtypes he described: squamous cell carcinoma, small cell carcinoma, large cell carcinoma and adenocarcinoma.[54] These are now considered in two main broader categories of lung cancer: small cell lung cancer (SCLC) and non-small cell lung cancer (NSCLC). NSCLC accounts for around 75-80% of all lung cancer diagnosed.[55] Optimal management differs for NSCLC and SCLC.[56]

1.3.1 Non-Small Cell Lung Cancer

NSCLC can be subdivided into adenocarcinoma (including bronchoalveolar) which account for around 30% of all lung cancers, squamous cell (around 30% of lung cancers) and large cell carcinoma.[54] Currently the treatment approach for patients with NSCLC is directed by the extent of disease staged[57] and the patient's fitness rather than histological subtype.[56] As treatments develop, with recognition of increased activity in

particular histological subtypes, the importance of histological subtype may increase.[58, 59] In Scotland, the age standardised incidence of adenocarcinoma has risen in both men and women since the 1970's.[34] In females the age standardised incidence of squamous cell lung cancer is also increasing but there has been a decrease in males.[34] Adenocarcinoma tends to present in the periphery of the lung (around 70%), arise from the surface epithelium or bronchial mucosal glands and have a well circumscribed appearance.[56] In contrast, squamous cell carcinoma of the lung tends to present centrally as an obstructing lesion within the large airways of the lung (60%).[56] Large cell carcinoma may account for around 9% of lung cancers,[54] but the reported incidence in surgically resected disease is only 2-3%.[60] They are often poorly differentiated but do not possess the typical appearance of a SCLC. Typically, they present as large peripheral masses, grow rapidly and metastasise early to the mediastinum and brain. Survival from large cell carcinoma is lower than from other NSCLC, even when comparing surgically resected early stage large cell disease to resected squamous or adenocarcimona.[61]

1.3.2 Small Cell Lung Cancer

SCLC tends to be an aggressive cancer that is clinically distinct from NSCLC. It is also known as 'oat-cell carcinoma'.[56, 62, 63] Small cell carcinomas occur predominantly in smokers and account for around 20% of all lung cancers. In Scotland the incidence of SCLC rose in males and females between the 1970's and the late 1990's.[34] The overall incidence is now beginning to decrease.[64] Untreated, SCLC has an extremely poor prognosis but in the 1970's new chemotherapy treatments were developed that raised the hope of it becoming a curable disease.[65] However, the good response to the initial chemotherapy does not often lead to persistent remission, and the disease often recurs rapidly. SCLC usually presents after a short period of symptoms and is generally associated with appreciable disease on the chest radiograph at presentation.[65] The lesions tend to be central, affecting large airways or the mediastinum and can be associated with superior vena caval obstruction (SVCO) and paraneoplastic syndromes.[66] As SCLC is rapidly progressive, the average survival of untreated limited stage disease (confined to the thorax) is less than three months. Untreated extensive stage SCLC has a life-expectancy of only six weeks.[56]

1.4 Management of Lung Cancer

Current guidance suggests, modern cancer care should be provided by a multidisciplinary team (MDT).[10, 55, 67-69] MDT working has not been evidenced through a randomised controlled trial but there has been widespread uptake of this method of working in cancer care.[70] The MDT has been defined as 'a group of health and social care professionals from a range of disciplines who meet regularly to discuss and agree plans of treatment and care for people with a particular type of cancer or problem, or in a particular location'.[10] The MDT, for lung cancer, should include a respiratory consultant (usually the lead clinician), an oncologist, a thoracic surgeon, a diagnostic radiologist, a pathologist, a specialist in palliative medicine and a specialist lung cancer nurse.[68]

Management includes prevention, diagnosis and communication of diagnosis, staging, prognostication, treatment, palliation and follow-up. There are national guidelines within the United Kingdom to set standards for speed of referral, investigation and time to treatment.[10, 67] The majority of lung cancer is diagnosed at an advanced stage.[55] Of 100 new presentations of lung cancer, only 20 (20%) would proceed to curative intent surgery and only five to ten of these patients will survive more than five years. The other 80 (80%) present with inoperable disease.[66] Thus, the issues relating to palliation, supportive care and dying often become relevant at the time of diagnosis.

1.4.1 Prevention

Primary prevention of lung cancer centres on discouraging commencement of smoking and, subsequently, cessation strategies for existent smokers.[71-73] Other approaches include chemoprevention, i.e. utilising natural or synthetic chemical agents to prevent, reverse or suppress development of cancer and harm reduction (limiting number of cigarettes or cigars smoked).[71, 72] The link between the incidence of lung cancer and smoking prevalence in populations can be seen across geographical, gender, socio-economical and ethnic divides.[29] There is a lag period of around 20 years in peak incidence of lung cancer after peak prevalence of smoking in each of these groups.[74]

The risk of passive smoking (exposure to environmental tobacco smoke) has been investigated over the last 25 years. Current evidence suggests a potential moderate increased risk from passive smoking but larger studies are likely to be required to confirm this difference.[24]

The epidemiological evidence is based on assessing consistency, strength of relationship, specificity, temporal relationship and correlation of lung cancer to smoking. There is now increasing direct evidence of the carcinogenic effects of smoking in the lung. Elucidation of one of the pathways by which this occurs has identified that the chemicals contained in cigarette smoke directly damage three specific loci on the p53 tumour-suppressor gene known to be abnormal in around 60% of lung cancer cases.[62] In Scotland, public policy has been used to reduce smoking. On Sunday 26th of March, 2006 a smoking ban in public places came into force.[75, 76] Other countries now have similar policies, including Ireland,[77] England[78] and Wales.[79]

1.4.2 Diagnosis

Pathways to diagnosis vary from patient to patient.[80] Recognition of lung cancer usually results from an initial presentation of clinical symptoms (>90% of cases are symptomatic at presentation).[81] The majority of patients are diagnosed through out-patient clinics (61%), others by being admitted to in-patient care as an emergency case (23%).[80] A smaller proportion (around 10%) have no index symptom and are diagnosed by incidental findings through routine investigations, occupational screening chest radiographs or as part of a 'life-scan' undertaken in a private health check.[80] Symptoms at presentation can be considered as directly related to the tumour, related to distant spread of the tumour or systemic effects of the cancer (weight loss, anorexia, fatigue).[66] The reported wide range of frequencies of presenting symptoms has been collated by Beckles, Spiro and Rudd (Table 3).[66]

Symptoms and Signs at Presentation	Range of Frequency %
Cough	8-75
Weight Loss	0-68
Dyspnoea	3-60
Chest Pain	20-49
Haemoptysis	6-35
Bone Pain	6-25
Clubbing of Fingers	0-20
Fever	0-20
Weakness	0-20
Superior Vena Cava Obstruction	0-4
Dysphagia	0-2
Wheezing or Stridor	0-2

Table 3: Range of frequencies of presenting signs and symptoms in lung cancer.[66]

Hamilton et al[82] studied 247 primary lung cancers presenting to general practices in England and compared these to 1235 control cases. This approach allowed the authors to evaluate symptoms associated with a diagnosis of lung cancer and calculate positive predictive values for single symptoms and combinations of symptoms compared to the controls. The most frequent presenting symptoms were cough (65%), dyspnoea (56%), chest pain (42%), fatigue (35%), weight loss (27%), haemoptysis (20%) and anorexia (19%). Only haemoptysis had a positive predictive value (PPV) greater than 2% (2.4%). If a second presentation occurred with haemoptysis, this PPV increased to 17%. The authors note that the recommendation of a chest radiograph for those with haemoptysis[10] is supported by these findings. It was also noted that there is a high background prevalence of respiratory symptoms in the primary care population which can make diagnosis difficult.[82, 83]

Once the suspicion of lung cancer has been raised, the diagnosis is usually confirmed by further radiological investigations and tissue sampling.[10] For all cancer management, there are three factors to be considered before appropriate treatment can be advised: the site of origin of the cancer, the type of cancer (histology) and the extent (stage) of the cancer. Determination of cell type in lung cancer can be achieved by obtaining tissue or cell samples utilising a range of invasive procedures: bronchoscopy[84] (washings, brushings, direct biopsy[85], transbronchial nodal aspiration (TBNA)[85] or biopsy directed through endoscopic bronchial ultrasound (EBUS))[86], percutaneous biopsy of lung lesion[87] or distant metastasis, aspiration of pleural fluid, oesophageal endoscopic ultrasound guided biopsy, mediastinoscopy biopsy, video assisted thoracoscopy (VATS), open lung biopsy or surgical resection.[10, 85] The most appropriate method of tissue sampling is considered the one most likely to produce a positive result with the least associated risks. This is likely to vary according to each individual's fitness, co-morbidities and the radiographic location of the suspected lung cancer.[67] In some cases, factors such as the patient's wishes, technical sampling issues or procedural risks, poor performance status, poor lung function or prohibitive co-morbidities prevent invasive tissue sampling procedures. In such cases, and in the absence of positive sputum cytology, the diagnosis is made on the basis of the clinical and radiological evidence. This may be referred to as a clinico-radiological diagnosis.

1.4.3 Staging of Lung Cancer

Staging is the 'assessment of the extent of disease and is performed for prognostic and therapeutic purposes.'[10] Most cancers can be staged according to the 'tumour, node and metastases' (TNM) system. The International Union Against Cancer (UICC) publishes a classification of cancers based on this system to allow international standardisation of assessment.[57] Lung cancer is staged using a combination of clinical, laboratory, radiological, and pathological investigations.[54] The extent of disease is evaluated by radiological investigations such as computer tomography (CT) scans,[88] magnetic resonance imaging (MRI)[85], positron emission tomography (PET),[89] radionucleotide bone scans, endobronchial ultrasound,[86, 90] transeosophageal ultrasound[91] and occasionally bone marrow aspiration.[10] As techniques develop, greater detail can be obtained to feed into multidisciplinary decision-making. This needs to be tempered with an efficient, efficacious and individualised approach to investigation.

1.4.3.1 Non-Small Cell Lung Cancer

The tumour, node and metastases (TNM) classification is the internationally accepted method of staging in NSCLC which was introduced in 1972. It was modified in 1997, and further revision occurred 2009.[88, 92, 93] TNM classification considers the size of the primary tumour and the extent of invasion, nodal involvement and presence of distant spread. Tumour status (T) is graded from zero to four (from absence (0) to increasing size and invasion), nodes (N) graded from zero to four (from absent to local to distant nodes) and metastases (M) are graded zero or one (absent or present). If any of these indices is unknown, it can be recorded with an 'x', i.e. Tx, Nx or Mx. Pathological staging (either after surgery or post-mortem) is indicated with the prefix 'p', i.e. pT, pN or pM. Clinical staging can be indicated with the prefix 'c', i.e. cT, cN or cM. Mountain classification can be used to further categorise TNM classification into stages 1 to 4 with 'A' and 'B' subtypes on the basis of similarities in ideal treatment and expected prognoses.[10, 56, 94] In this classification, stage 1 disease is the least advanced with localised disease only, ranging to stage 4 disease with distant metastases[10, 56] (Figure 4).

When no metastases present (M0)

N3	3B	3B	3B	3B
N2	3A	3A	3A	3B
N1	2A	2B	3A	3B
N0	1A	1B	2B	3B
	T1	T2	T3	T4

Stage 4, any T or N with metastases (M1)

Figure 5: Mountain classification of stages of lung cancer utilising the TNM system to assign stages 1A, 1B, 2A, 2B, 3A, or 3B (when no metastases present) or Stage 4 (when any metastases present).

'Early stage' lung cancer is considered to include stages 1A, 1B, 2A and 2B, and 'locally advanced' lung cancer refers to stages 3A and B. Potentially curable disease is considered as stages 1 to 3A.[88] In general, stage 1 and 2 disease is amenable to surgical resection if the patient wishes and has adequate fitness and pulmonary function to tolerate an operation. Selected patients with stage 3A disease may also be offered surgery (often in combination with another treatment modality). Those with stage 3B and stage 4 disease are considered to have incurable disease.[92, 94] Overall prognosis worsens as the stage of disease increases.

1.4.3.2 Small Cell Lung Carcinoma

The TNM system can also be applied to SCLC. However, a further staging system is currently more commonly used within the clinical setting. The Veterans Administration Lung Group system stages SCLC as either: 'limited' or 'extensive' disease.[65] This staging determines both treatment options and prognosis.[62, 65] Limited disease is defined as 'disease confined to one hemithorax and regional lymph nodes that can be encompassed by a reasonable radiation field' and extensive disease is defined as 'disease which has spread beyond the definition of limited stage'.[10] The majority of patients with SCLC present with extensive disease.[10]

1.4.4 Treatment of Lung Cancer

1.4.4.1 Treatment of Non-Small Cell Carcinoma

NSCLC has a slower doubling time than SCLC. This, combined with a relatively lesser tendency to disseminate, makes surgery the best curative option whenever possible.[56] It should be considered for those with stage 1-3A of NSCLC depending on the patient's wishes, performance status[95] (PS), co-morbidity and lung function. At diagnosis, less

than 20% of patients are suitable to undergo resection, limited by either disease extent or fitness for surgery.[55] Despite the curative intent, less than 50% of those who do undergo surgery survive five years,[92, 94, 96] with the majority dying of metastatic disease.[96] Radical radiotherapy (with curative intent) may also be offered to those with stage 1 or 2 disease when they are unable to tolerate (or do not wish) surgical resection. For individuals with good PS (0 or 1) and less than 10% weight loss, radical radiotherapy can also be considered in stages 3A and 3B.[68] At diagnosis, the majority of patients do not have curable disease and, as such, treatments have palliative intent. Treatment goals focus on lengthening survival, improving quality of life (QOL) or obtaining symptom control. Options in this situation include systemic chemotherapy, palliative radiotherapy and palliative and supportive care.[55, 97]

1.4.4.2 Treatment of Small Cell Carcinoma

Due to the systemic nature and rapid doubling time of SCLC, surgery is rarely an option.[88] Patients are considered for chemotherapy and/or radiotherapy and these are delivered within the limits of patients' wishes and fitness for therapy. These treatments prolong survival but recurrence is frequent.[55] Within Scotland, the median survival for SCLC was around 3.5 months when studied in 1995.[41] This is lower than the median survival seen in other countries for reasons that are likely to be multi-factorial, including treatment uptake and co-morbidity.[98] Patients who are fit enough and have extensive stage disease (that responds to first line chemotherapy) or limited stage disease with observed response to chemotherapy can be considered for Prophylactic Cranial Irradiation (PCI) to prevent occurrence of brain metastases, reduce symptoms, increase disease free interval and extend survival.[99]

1.4.5 Prognostication in Lung Cancer

The art of medicine has been described as containing three core elements: diagnosis, prognosis and therapeutics. Prognostication is increasingly becoming part of good cancer care and facilitating clinical decision-making.[100, 101] Prognosis is determined by the interplay between the tumour, the host and environmental factors. Environmental factors refer to treatments undertaken, the system in which the patient is cared for and wider societal factors such as socioeconomic status. All these factors can be further subdivided as either 'essential' (those fundamental to decision-making) or 'additional'

(factors that allow finer prognostication beyond those needed for treatment decisions).[101]

There has been a great deal of study in the area of prognosis for many cancers, including lung cancer, and at the different stages of the cancer journey. A recent systematic review of the literature identified over 150 different prognostic factors in NSCLC.[100] For overall survival, the TNM system has consistently been shown to be the most powerful prognostic tool.[92, 94] The review stratified patients into those with advanced disease, locally advanced disease (cancer that has spread to nearby tissue or lymph nodes) and potentially resectable disease.

Within the advanced disease category for NSCLC, the essential factors include: extent of disease, performance status[102, 103] and weight loss.[104-106] Additional factors include: refinement of anatomical cancer distribution, age, haemoglobin, lactate dehydrogenase (LDH), albumin, C-Reactive Protein (CRP)[104-110] and gender. Further work has also evaluated other prognostic factors such as coagulation, proteinuria, marital status, quality of life (QOL), mood and symptom burden.[104, 111-120] It is of note that research focusing on QOL has led to the development of renewed interest in symptoms and symptom burden as a prognostic indicators.[121]

The majority of patients presenting with locally advanced disease have systemic symptoms such as reduced PS and weight loss. In this situation most studies consider prognostic factors to be the same as for metastatic disease.[100] For patients without systemic signs or symptoms, there is evidence of higher survival rates, and these patients may represent a different prognostic group.[122]

The category of operable NSCLC has received less attention in terms of prognostic investigation. The focus has been on accurate staging and determining fitness for surgery. There has been a great deal of study of those who have already undergone surgery, even though this represents the minority of patients. Again, tumour related factors are the main determinant of prognosis, particularly completeness of resection and pathological staging.[94, 100] There is some evidence that markers of systemic inflammation (e.g. CRP) could be used to aid prognostication in patients undergoing surgery.[123, 124]

In SCLC the distinction between limited and extensive stage disease remains the main determinant of prognosis. In limited disease, prognosis is predicted by PS, gender, age and LDH.[101, 125, 126] Prognostic scores have been developed to aid assessment for treatment. One such score is the Manchester Score which utilises lactate dehydrogenase, tumour stage, performance status, alkaline phosphatase and serum bicarbonate to distinguish three pre-treatment prognostic groups (the best group contained all long-term survivors and in the worst group no patient survived more than one year).[126] This score and the importance of these variables have been validated in subsequent studies.[127, 128] Concurrent chemo-radiotherapy has been shown to improve median survival.[98] In extensive stage disease, the best predictors of survival are normal LDH, response to combination chemotherapy and having a single metastatic lesion only.[62, 101] Patients in the terminal phase of their disease (defined as those with predicted survival of less than three months) are considered differently than those with localised or advanced cancer. At this point in the illness trajectory[129] many prognostic factors have reduced importance.[101] It has been reported that type of cancer and tumour-related factors are less relevant for prognostication than functional status and particular symptoms, especially anorexia, weight loss, dyspnoea, xerostomia and delirium.[130-136] Within advanced cancer (not specifically lung cancer) there may still be a role for the use of blood markers representing systemic inflammation, such as CRP.[137]

1.4.6 Follow-Up in Lung Cancer

After the diagnosis is made and treatments discussed and administered, follow-up is often arranged for patients. Follow-up may aim to serve several purposes but currently lacks a strong evidence base for effectiveness.[138] Within cancer care across different settings and for different tumour types, a variety of follow-up structures and methods exist. The main purposes served by follow-up include:

- assessing response to treatments provided;
- monitoring for complications of treatments;
- surveillance for recurrence of treated cancer;
- surveillance for second or new cancers in higher risk groups;
- provision of supportive care;
- prevention of complications or recurrence.

A review of the current evidence for follow-up and different follow-up structures has been undertaken (see Section 4).

1.4.7 Supportive and Palliative Care in Lung Cancer Management

The terms 'supportive care' and 'palliative care' are used widely within the literature. They can be defined as separate entities with differentiation based on the prognosis (which is more limited in palliative care), the presence of active treatments (often considered supportive care) or treatments to control symptoms only (palliative care). There is a great deal of cross-over between these terms and some authors would make no major distinction between them.

1.4.7.1 Supportive Care

'Supportive care' is considered to be part of good management of lung cancer.[139] 'Best supportive care' is a term now often utilised to describe the default or standard arm of many clinical trials within the oncology setting.[140] Supportive care can be defined as:

> *Care that helps the patient and their family to cope with cancer and the treatment of it – from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps maximise the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment.*[141]

This broad definition emphasises that care encompasses both the patients and their families. It affirms that supportive care integrates into the full cancer journey from pre-diagnosis to cure and survivorship or to end of life and bereavement care. It makes clear that this is not in opposition to, or less important than, other treatments for cancer but fits alongside and can help 'maximise' their benefits. This builds on a previous definition of supportive care provided by the European Organisation for Research and Treatment of Cancer (EORTC) Pain and Symptom Control Task Force:

> *Supportive care for cancer patients is the multi professional attention to the individual's overall physical, psychosocial, spiritual and cultural needs, and should be made available at all stages of the illness, for patients of all ages, and regardless of the current intention of any anti-cancer treatment.*[142]

The EORTC definition makes the domains of need clearer: physical, psychosocial, spiritual and cultural. However, there is no clear method for best identifying individuals' supportive care needs, and there is little standardisation in care provision. This lack of clarity has been recently critiqued in the context of lung cancer clinical trials where 'Best Supportive Care' has been compared as a control to new active anticancer treatments.[140] The authors of this paper argue that without a clear and

standardised definition of best supportive care, assessment of new treatment benefits is significantly affected and wider comparisons across different trials are hindered.

1.4.7.2 Palliative Care

Palliative care can be defined as:

> *The active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and the provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of illness in conjunction with other treatments.*[141]

Specialist palliative care is defined as:

> *The active total care of patients with progressive, far advanced disease and limited prognosis and their families, by a multiprofessional team who have undergone recognised specialist palliative care training. It provides physical, psychological, social and spiritual support, and will involve practitioners with a broad mix of skills.*[10]

In these definitions palliative care has been distinguished from supportive care. However, there is overlap between the areas of general palliative care, specialist palliative care and supportive care. Patients should have access to specialist palliative care services throughout their cancer journey.[10, 129, 143] It is likely that the palliative care services will become more involved in care as the cancer becomes advanced. However, they can play a significant role at any point within the disease journey.[12, 13, 129, 143, 144] Within the care guidelines there is a clear emphasis on good communication and smooth transitions of care between specialities. This could be developed further into models of integrated working. However, this area has not been well studied although there are some examples of coordinated care from diagnosis.[144, 145] A recent position paper from the European School of Oncology has gone further in defining the right to good supportive care of each cancer patient, stating that 'When a patient has difficult symptoms which cannot be controlled by his/her current healthcare team, *he/she has a right to be referred*, and the current healthcare provider *has an obligation to refer*, to the local specialised palliative care team'[143] (emphasis added).

1.4.7.3 Assessment of Supportive Care Needs

Supportive care needs in cancer patients are diverse and may fall into several domains: psychological, information and communication, physical (symptoms and function),

practical and spiritual. 'Needs' have been defined as having 'the requirement of some action or resource that is necessary, desirable or useful to attain optimal well-being.'[146] Symptom assessment may identify the presence of symptoms (and now also the associated distress). Quality of life assessment can identify domains of reduced quality and satisfaction assessment can identify areas of low satisfaction. These do not usually assess which issues patients want help or support with. Needs assessment differs by identifying issues that patients do want help with and may allow the patient to indicate the magnitude of importance of each issue or identify areas which cause the most disturbance to the patients' lives. Patient's choice, prognosis, quality of life and symptom burden are central in the clinical care of lung cancer. These issues drive decision-making and transitions of care.[143]

It is of note, however, that not all patients do want help from health care services for all care needs. In a qualitative study, Steele and Fitch evaluated the underlying reasons that some lung cancer patients did not want help for unmet supportive care needs.[14] In their questionnaire (n=59) and semi-structured interview-based study (n=34), several key themes were identified underlying patients not seeking help for certain needs. These included: an ability to manage by themselves, assumption that certain symptoms or needs were 'to be expected' in lung cancer, existence of strong support networks to deal with issues and retain privacy, recognition of the high workloads of professionals and self-prioritising of needs to reduce added burden to health care teams, lack of awareness that resources were available to draw upon and trust in health care teams that they would identify and broach issues of importance. The quality of supportive care can be considered to be the extent to which needs are addressed. To allow patients who do wish help with unmet needs to access appropriate resources, it is important to be able to assess supportive and palliative care needs and to measure the success in meeting those needs.[147, 148]

The recent National Institute for Health and Clinical Excellence (NICE) guidance on providing supportive and palliative care to cancer patients stressed the importance of standardised and systematic assessment of such needs at regular intervals in its second recommendation:

> *Assessment and discussion of patients' needs for physical, psychological, social, spiritual and financial support should be undertaken at key points (such as at diagnosis; at commencement, during, and at the end of treatment; at relapse; and when death is approaching). Cancer Networks*

should ensure that a unified approach to assessing and recording patients' needs is adopted.[143]

Richardson et al[149, 150], completed a time-limited, systematic review of 'needs assessment tools', identified between 1984-2004 to aid the process of meeting this recommendation in England and Wales. They defined 'assessment' as 'collecting information on a person's needs and circumstances and making sense of that information to identify needs and decide on what support or treatment to offer.' This definition was further refined to specify the process should: be from or with the patient; have a consistent framework; be systematic in timing; be based on patients' accounts of their needs, wishes and expectations; and inform the multidisciplinary team involved in care.

Fifteen different tools were identified and reviewed. Of these 15, only three were specifically developed to identify needs which patients *wanted* help with: the Cancer Care Monitor (CCM),[151, 152] the Sheffield Profile for Assessment and Referral to Care (SPARC)[153] and the Initial Health Assessment (IHA).[154] CCM, a computer-based tool, was developed to screen for cancer-related symptoms, treatment toxicities and patient concerns. SPARC was specifically developed to identify palliative care needs to direct appropriate and timely referrals to specialist palliative care services.[153] IHA was designed to act as a clinical tool to identify supportive care needs during a patient's first visit to a cancer care centre. The other tools within the review were developed to identify the experience of a problem, or presence of dissatisfaction, without identifying a wish for the need to be met.

The authors of this review identified the Palliative Outcome Scale (POS) as an outcome measure tool designed to assess the effectiveness of palliative care interventions. As such, it was excluded from the systematic review. However, it is not clear why the baseline evaluation of supportive care needs requiring intervention would not qualify as an assessment tool. Wen and Gustafson[155] have conducted a similar systematic review but widened the criteria to include tools that assessed supportive care needs of patients and their families. In this review, seven further tools were identified which evaluated the supportive care needs of the family.

1.4.7.4 Supportive Care Needs in Cancer and Lung Cancer

A broad systematic review by Harrison et al[156] outlines a wide range of prevalence of unmet supportive care needs in cancer patients. Ninety-four articles were reviewed, including one randomised control trial, one cohort study, 41 surveys and 52 other qualitative studies (interview- and focus group-based). A variety of tools have been used, preventing a standardised view over the cancer journey. Tools which identified need or inferred need were included.

The majority of studies evaluated patients undergoing treatment (n=25). In this phase of the cancer journey, variable prevalence of unmet needs were identified in specific domains: activities of daily living needs (4-89%), communication issues (2-57%), economic needs (13-54%), information needs (11-97%), physical (21-70%), supportive care (13-86%) and sexuality (49-63%). The authors note that the upper range of prevalence of each domain was greatest in these studies compared to other phases of the cancer journey. They also note this may be an effect of more studies evaluating this phase.[156]

At diagnosis, a narrower range of prevalence was found in each observed domain: activities of daily living needs (5-10%), economic needs (11%), information needs (10-24%), physical (44%), psychosocial (6-69%) and psychological (12-17%). The authors note that a small number of studies address this phase of the cancer journey (n=3). Nine studies evaluated the advanced or palliative phase of the cancer journey and a further 14 studies focused on post-treatment, follow-up and survivors. Lung cancer has been identified as having greater associated supportive care needs in comparison to other cancer types.[146] Harrison et al[156] also note that on secondary analysis of reported unmet supportive care needs of patients with cancer by Sanson-Fisher et al,[146] lung cancer patients have an overall higher burden of supportive care needs compared to all other patients and to those being treated for breast cancer, prostate cancer, colorectal cancer or malignant melanoma.

Supportive care needs in lung cancer have been studied previously. Krishnasamy et al[13] utilised a postal survey to identify health care needs in this population. One hundred and fifty-nine patients (of 466 invited participants) responded to the survey. Forty two percent of the respondents had undergone surgery for lung cancer (skewing this sample towards early stage, resectable disease). They found only 40% of patients reporting they

had ‘as much help as they needed’ from community services. Personal anxiety was a key problem in 66% of respondents but only recognised as such by 23% of hospital consultants. Other symptom issues identified were: pain (89%), unusual tiredness (85%), dyspnoea on walking (80%), cough (70%), insomnia (59%), anorexia (49%) and depression (49%). Social issues were identified as a problem in 58% of respondents. When asked to identify sources of support, most patients (76%) identified hospital consultants as the lead source of support. Other sources of support were identified as husband/wife/partner (65%), son/daughter (55%) and hospital nurse (48%). In this group of patients, only 6% identified specialist nurses as providing support. Communication issues were also identified; in particular, the giving of clear information to significant others was lacking. However, 71% of patients had been told their diagnosis by a hospital consultant and, overall, 69% felt their diagnosis had been given either sensitively or very sensitively.

In a secondary analysis of a larger survey (888 respondents to 1492 invitations) of Australian cancer patients, Li and Girgis[157] evaluated supportive care needs in lung cancer patients (n=112). This survey used the supportive care needs survey (SCNS)[158] and found lung cancer patients reported higher mean numbers of unmet psychological, physical and activities of daily living needs than all other patients (patients with breast, bowel, prostate, melanoma and other malignancies). There were similar levels of unmet needs in domains of health information and sexuality.

The three most prevalent psychological needs reported by lung cancer patients were: ‘concerns about the worries of those closest to you’ (53.4%), ‘fears about the cancer spreading’ (52%) and ‘fears about physical disability or deterioration’ (49.5%). Of note, in all other patients, these three issues were also the most prevalent but at lower levels (33%, 36.1% and 36.6% respectively) and in reverse order.

The three most prevalent physical needs reported in lung cancer patients were: ‘not being able to do the things you used to do’ (53.3%), ‘lack of energy/tiredness’ (48%) and ‘pain’ (38.8%). Other patients also reported these as the most prevalent three issues but again at lower levels and ranking them as lack of energy, then not being as able to do the things you used to do, then pain.

Logistic regression was used to assess predictors of unmet physical and psychological needs. Having a diagnosis of lung cancer was an independent predictor of high levels of psychological (relative risk ratio=2.00, 95% CI 1.13-3.56) and physical needs (relative risk ratio=2.81, 95% CI 1.60-4.95). The authors conclude that the results clearly show there is a significantly higher burden of unmet supportive care needs reported by lung cancer patients compared to other malignancies. The study recruited patients from out-patient clinics but has not specifically reported or controlled for the performance status of patients.

Hill et al[11] used a modified version of The Concerns Checklist[159] alongside an interview completed within 28 days from diagnosis (n=80). All patients in the study rated at least two items as worrying to them (median 9 concerns, range 2-17). The highest rated concerns included: worries about the illness, worries about family and worries about future events related to the illness (defined as major worries ranging from very worried to extremely worried). Moderate worries included: feeling a burden to others, low energy, emotional issues, treatment concerns, dyspnoea, pain and mobility. Minor worries included cough, appetite, bowel issues and nausea and vomiting. It was noted that patients felt only 43% of their reported concerns had been considered by the healthcare team. Of the issues addressed, the majority related to symptoms and not psychosocial issues. Exploring this further, the authors rated concerns as 'adequately discussed' if more than 50% of patients reported having discussed the issue. Using this scale they found 70% of symptoms had been 'dealt with' but *none* of the emotional, psychological or social concerns had been adequately discussed.

The findings of Hill et al[11] in 2003 are in keeping with the study of Houts et al[6] in Pennsylvanian cancer patients from 1986. Houts et al[6] study of psychological, social and economic unmet needs reported a high level of need in cancer patients. Unmet emotional needs were most frequently reported (25%), followed by financial (13%), social (12%), issues related to medical staff (10%), family (8%), spiritual (7%) and information (6%). On regression analysis, it was found that having a diagnosis of lung cancer was independently associated with having higher overall unmet needs and higher unmet needs in each of four domains: emotional/social, economic, relations with medical staff and community. A diagnosis of colon, breast, uterine or prostate cancer was not independently associated with higher overall needs. Other characteristics

predicting higher unmet needs included: higher stage of disease at diagnosis, being younger, lower income and emotional problems pre-dating the diagnosis of cancer.

Unmet supportive care needs in Pennsylvania between 1986 and 2005 have been re-evaluated by Barg et al[5] (Houts is also one of the authors of this paper). Although a comparison was not directly possible (altered survey method and patients included could be further from diagnosis), the authors were able to make some assessment of changes in unmet needs. They report that overall there had been very little improvement in needs being met and, indeed, there may have been an increase in unmet needs since 1986. In this study, they did not look at specific cancer types. Steinberg et al[160] have reported in 2009 that 'distress' is evident in 51% of newly diagnosed lung cancer patients. In this model, physical symptoms did not contribute to prediction of global distress, but 42% of the variability in distress is predicted by the psychosocial variables 'depression' and 'nervousness'.

1.5 Symptom Control

Symptom control is a major component of supportive care.[161] The following section outlines some of the concepts regarding symptoms and symptom burden. It gives a further overview of symptoms in lung cancer and the psychosocial context in which they are experienced. A review of the literature regarding specific symptoms in lung cancer is presented in Section 5.

1.5.1 Symptoms and Symptom Experience

'Symptom' is a term that can be interpreted in many ways and used for different purposes. The origin of the word comes from the Latin *symptoma* (meaning 'from') and the Greek *sumptoma* (meaning 'chance'). These derive from *syn* and *piptein* meaning 'that which has befallen one.'[121] The biomedical approach to symptoms understands the term to represent perceived changes in the body, or its functions, that indicate disease or different phases of disease.[162] The Collins dictionary defines symptom in a biomedical way as 'any sensation or change in bodily function *experienced by a patient* that is associated with a particular disease'[121, 163] (emphasis added). A medical anthropological perspective looks at symptoms as representations of the meanings that illness has for the person experiencing them.[162] In this perspective, there is a distinction made between the 'disease process' (i.e. physical, structural or pathophysiological changes), the human

experience of 'illness' and the behavioural and psychological expressions of these within each person's social and societal structure.[162] Supportive and palliative care utilise the multidisciplinary team to approach care with a wider view of symptoms and symptom experience, encompassing both biomedical and medical anthropological approaches.[142]

Symptom experience, or symptom burden, has been described as a summation of symptom *occurrence (frequency and intensity)* and the *distress* felt related to that occurrence.[121, 164, 165] Frequency, duration, severity, meaning and memory of symptoms will influence the impact on each individual. In this meaning-centred approach, distress is the impact experienced from the presence of the symptom burden.[164, 166] Symptom experience has also been described as a dynamic process that involves the perception, evaluation, meaning of and response to a symptom.[166] This response takes place within the patient's individual psychosocial context.[166]

Symptom burden can be defined as a summative indicator of 'the severity of symptoms that are most associated with a disease or treatment' and 'a summary of the patient's perception of the impact of these symptoms on daily living, including activity, mood, ability to work, and ability to relate to others.'[121] Within these definitions, there is an emphasis on symptoms being subjective and, thus, the resulting burden and distress are individual.

This dynamic process of symptom experience is further complicated by subtle disparities between recognition of distress by carers and professionals and distress felt by patients. Although there is a general agreement between patients and significant others in the assessment of general well-being and function, for concrete observable symptoms the significant other often reports higher symptom levels and more problems than the patient. This disparity is particularly true for assessments of psycho-emotional function.[167] Throughout the lung cancer trajectory, there is evidence of these subtle discrepancies. Lobchuk et al[168] described some congruence between patient-reported symptoms and carer-reported symptoms. There was, however, a difference when the symptoms were ranked according to reported intensity. Of particular note, it was found that for most symptoms caregivers rated the intensity higher than the patient.

This has been explored further by Broberger et al[169] and subsequently by Wennman-Larsen et al.[167] In the first of these studies, both symptom distress and ratings of symptom occurrence were compared between lung cancer patients and caregivers. The authors found that there was general agreement about which symptoms might cause distress but a lack of congruence in rating of symptom occurrence. Again caregivers rated more frequent symptoms than patients.

In the second of these studies, the factors influencing agreement in symptom ratings were investigated, again finding a higher rating by caregivers. For many symptoms it was noted that although in grouped studies moderate overall agreement suggested this may allow proxy assessment of symptom distress, this might not hold true on an individual basis. Factors of importance in congruence included: gender (female caregivers tended to match patient's ratings better), rating of fatigue and rating of emotional functioning.

Lack of congruence has also been observed in the last week of life in the cancer setting. Oi-Ling et al[170] showed disparity between patient-rated, professional-rated and caregiver-rated symptom distress. It was found that health care professionals underrated many symptoms. This observation was also made in a study looking at symptom distress rated by patients with advanced cancer and their caregivers in the hospice setting.[171] Given these disparities, when it is possible to assess symptom experience by patient-reported measures, then this should be used in preference to proxy reports.

1.5.2 Symptoms in Lung Cancer

Symptoms in lung cancer often act to prompt investigations leading to investigation and diagnosis,[80, 82] contribute to changes in global quality of life[172] and may aid prognostication at different phases of the cancer trajectory.[116, 173] A review of the literature regarding symptoms in lung cancer is presented in Section 5.

Several studies have shown that patients with lung cancer experience more symptom distress than other cancers and many chronic conditions.[1, 12, 104, 114, 119, 174-177] There is a decline in function and an increase in symptom burden as the cancer advances.[12, 178, 179] A recent study of patients with advanced cancer by Johnsen et al[175] found lung cancer was a significant independent predictor of dyspnoea and reduced social function. It has been estimated that 25% of lung cancer patients have depression or other psychosocial

needs which are unmet but are amenable to intervention.[2] Those who are not offered anti-cancer treatments, and patients with SCLC, are at higher risk of psychosocial morbidity.[2] It has also been found that there is an early peak in distress around the time of diagnosis.[1, 174] Furthermore, there is a complex interplay between the cancer journey and physical and psychosocial disease trajectories.[129, 180]

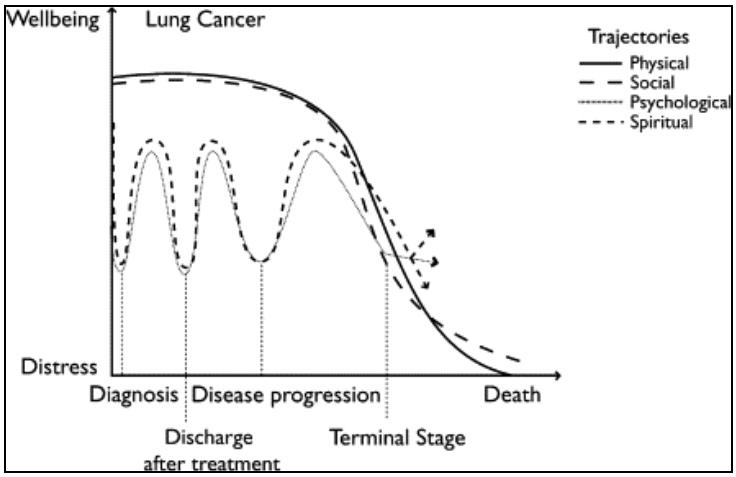


Figure 6: Lung cancer: physical, social, psychological and spiritual well-being in the last year of life.[180] Reprinted from *The Journal of Pain and Symptom Management*, Copyright 2007, with permission from Elsevier.

1.5.3 Why is Supportive Care of Importance in Lung Cancer?

Lung cancer stands out from other cancers and conditions as a disease of high symptom burden and increased psychosocial morbidity. Having lung cancer has been reported to be an independent predictor of distress in comparison to other cancers[4-6, 146, 157] and non-malignant conditions.[181, 182] The majority of patients have incurable disease at presentation and, of the few who could be offered curative treatments on the basis of staging, many are not fit for such treatments due to comorbidity. As such, these burdens of lung cancer are faced in the context of a poor survival and a high mortality. Despite this, current models of lung cancer care often do not address supportive care issues adequately[12, 13] or at all.[11] Considering these factors, the importance of providing timely, efficient and effective supportive care is very clear.

The aims of this study have been established to assess the current need within the Stobhill lung cancer service, to identify factors that may help improve services and to establish patients' views on models of care (Section 2).

1.6 Summary of Introduction

Over the last one hundred years, lung cancer has developed from a rare condition to become a worldwide epidemic. Lung cancer is now the leading cause of cancer-related death within Scotland, the United Kingdom and worldwide. In Scotland, lung cancer is diagnosed in over 4000 people each year and accounts for over 25% of cancer related deaths. Compared to many other cancers, lung cancer is associated with higher symptom burden, increased psychosocial distress, reduced physical function and worse survival. These issues may be further compounded by co-morbidities and high levels of deprivation within the lung cancer population.

The term 'lung cancer' describes a number of different pathologies. The different types can be broadly classified into two divisions based on cell types: non-small cell lung cancer and small-cell lung cancer. Further distinction can be considered using sub-types of cell and the extent of the disease in any individual. The management options may vary according to type of cell (and increasingly sub-type), the stage of disease and the patients' fitness to tolerate any given intervention. Individual prognosis also varies according to cell type, stage and physical function at diagnosis. In the UK, multidisciplinary care is now considered the gold standard for lung cancer management in order to achieve a holistic approach to lung cancer. Although patient-centred care is being promoted through UK government policy, there remains a deficit in the recognition of the needs of many lung cancer patients.

This lack of recognition is mirrored by the large proportion of supportive care needs remaining unmet within this population. However, palliative and supportive care is increasingly being recognised as a vital part in cancer management. Such care is now being integrated into routine clinical care from diagnosis and into end points within clinical trials. These end points may include symptom burden (or distress) or quality of life and are increasingly assessed by patient-reported outcome measures. The relationship between symptom burden and quality of life is an area of current study.

Within lung cancer there is a wide variation of reported symptom prevalence throughout the disease trajectory. Recently, the concepts of symptom burden and symptom distress have been developed to aid assessment of the occurrence, severity, frequency and associated impact of such symptoms. A wide variety of measurement tools have been used to allow some insight into physical and psycho-emotional symptoms. The role of

symptoms within the detection and management of lung cancer is pivotal and may also provide further prognostic information. The role of symptoms in follow-up is well described, but there remains discussion regarding the use of symptom driven follow-up instead of routine clinico-radiological follow-up.

Patient reported outcome measures are now being used within clinical and research settings to aid individual management, identify items of unmet need, facilitate clinical audit and direct service development. The Palliative Outcome Scale is one such measure which has been developed and validated to assess supportive care need domains in advanced cancer. There may prognostic value in assessing symptom burden and quality of life. As such, POS may serve the dual purpose of identifying supportive and palliative care needs of lung cancer patients in the hospital setting and aiding prognostication.

The aims of this study are outlined below (Section 2) and the process of development and methodology is described in Section 3.

2 Aims

This aims below set out how this study hopes to answer the question:

What are the supportive care needs within the lung cancer population attending the Stobhill Hospital multidisciplinary lung clinic and are there identifiable factors which can aid service provision to meet these needs?

Primary Aim

1. To evaluate the prevalence of supportive care needs within Stobhill Hospital's lung cancer multidisciplinary clinic, to assess overall supportive care needs as measured by the Palliative Outcome Scale and to identify the key issues reported by patients in three groupings (Sections 6.1-6.2):
    a. all lung cancer patient attending the clinic,
    b. newly diagnoses lung cancer patients (within six weeks of diagnosis) and
    c. patients within the last three months of life.

Secondary Aims

2. To review the literature regarding symptoms related to lung cancer (Section 5).
3. To review the literature regarding the current guidance and evidence for follow-up in lung cancer (Section 4).
4. To evaluate clinical indices used within the Stobhill service to help identify patients with:
    a. increased supportive care needs overall as measured by POS (Section 7),
    b. a reduced survival (Section 8) and
    c. increased risk of key supportive care needs:
        i. increased anxiety and worry (Section 9),
        ii. pain (Section 10) and
        iii. dyspnoea (Section 11).
5. To evaluate the Stobhill lung cancer service regarding (Section 6.2):
    d. service usage,
    e. patients' satisfaction with the service,
    f. patients' understanding of the follow-up provision and
    g. patients' preferences for follow-up.
6. To make recommendations regarding (Section 12):
    h. areas for development of the Stobhill lung cancer service to meet supportive care needs and
    i. future study and research.

3 Methods

This section describes the methods employed and the design of this study. It outlines the population within the Stobhill lung cancer service that was evaluated and the setting in which this study took place. It describes the methodology used to allow evaluation of the three groupings of interest: all patients attending the clinic, newly diagnosed patients and those within the last three months of life. It details the approach to meeting the aims of the project and the process of development of this project. It also outlines the ethical framework within which the project operated.

Two main literature reviews were undertaken to understand the symptoms lung cancer patients face and the current evidence regarding follow-up (Aims 2-3). These reviews provide a platform from which to consider active symptoms within the Stobhill lung cancer population and an understanding of the follow-up process that could inform possible integration of future supportive care provision.

Within this study a questionnaire and case note review were used. The questionnaire was introduced into the Stobhill clinic to aid supportive care needs assessment, surveillance for active respiratory symptoms and to understand patients' views of the service. The processes of project development (Section 3.3) and questionnaire development are outlined below (Section 3.7.2). The questionnaire contained an adapted Palliative Outcome Scale (POS) but also included the addition of questions regarding respiratory symptoms and service views. The modification of the tool may have reduced the validity of the questionnaire, and that has given rise to methodological issues that limit the scope of the conclusions. However, the use of non-validated instruments has been described as providing 'important information about symptom prevalence and severity', and the process of validation of cancer symptom assessment tools has varied considerably.[183] The limitations of using a non-validated tool are discussed in Sections 3 and 12.

Defining the difference between service evaluation, audit and research can often be difficult.[184, 185] Therefore, the ethical status of this study was determined through discussion, guidance from the University of Dundee,[186] due process outlined by the National Research Ethics Committee,[184] advice from the relevant Local Research Ethics Committee (LREC) Chairperson and subsequently full consideration by the LREC. It

was determined full ethics approval was not required and the study should proceed under service evaluation status (Appendix 1).

The questionnaire provided quantitative outcomes that were analysed by descriptive statistics, univariate tests of association and multivariate regression. The approach to the analysis is outlined in Section 3.

3.1 Literature Reviews

In Section 1, the history and epidemiology of lung cancer has been described. The management of lung cancer has also been outlined. Lung cancer patients face a journey full of difficult decision-making regarding their own management. These decisions are made in the context of a high symptom burden. A review of the literature regarding symptoms in lung cancer has been completed (Section 5 and Aim 2).

Within the management of lung cancer, follow-up is uniquely positioned to allow provision of supportive care. A review of the literature regarding lung cancer follow-up has been undertaken to understand the current evidence and practice from which models of care can be developed (Section 4 and Aim 3).

3.2 Description of Study Setting

Stobhill Hospital is located in the North of Glasgow, Scotland and has approximately 440 in-patient beds. Its catchment area covers a population of more than 200,000 people within the North of Glasgow and part of East Dumbartonshire.[187] This population includes many of the most deprived people in Scotland, with Glasgow City containing almost half (48%) of the 15% most deprived local populations in Scotland.[188] As outlined previously, Glasgow has the highest incidence of lung cancer and the highest lung cancer-related death rate in Scotland. This places Glasgow as a lead in lung cancer experience within the United Kingdom. In global terms, Scotland has one of the highest incidences of lung cancer worldwide.

In addition, it is likely that lung cancer patients in Glasgow have higher levels of co-morbidity than other areas within the United Kingdom. This may, in part, explain the lower rates of active anti-cancer treatment and the higher death rates in Glasgow than in other areas within Scotland.[41] Given the high incidence and poor prognosis of lung

cancer patients attending the Stobhill clinic and their associated high levels of co-morbidity and deprivation,[189, 190] lessons learned from understanding this service may inform other services.

The Stobhill multidisciplinary lung cancer clinic, established in 1991, was the first lung MDT clinic in Scotland. It is available weekly and follows an MDT meeting attended by the respiratory team (consultant, trainee doctors and a lung cancer specialist nurse), radiology consultants, an oncologist, a thoracic surgeon, a palliative care consultant, a pathologist, clinic nurses and a cancer journey auditor. This meeting serves as a platform to discuss cases and make clinical team decisions. It also provides a forum for cross-specialty education and discussion.

The majority of patients attending the clinic already have a definite diagnosis. This includes patients with both lung cancer and mesothelioma. A minority of patients attending the clinic are awaiting final investigations, repeat tests or serial CT scans to fully determine the diagnosis. The clinic follows on immediately after the MDT meeting and operates to allow assessment of the patients by the respiratory team, oncology team or the lung cancer specialist nurse. Surgical reviews are by arrangement and palliative care reviews by referral to an external clinic, home review or in-patient ward review. Patients may be newly diagnosed, receiving active anti-cancer treatment, being reviewed post-treatment, under routine follow-up or receiving supportive care. As such, there is a diverse range of lung cancer journey stages and supportive care needs represented within this clinic population.

3.3 Development of this Study

The primary aim of this study is to evaluate the prevalence of supportive care needs within Stobhill Hospital's lung cancer multidisciplinary clinic, to assess overall supportive care needs as measured by the Palliative Outcome Scale and to identify the key issues reported by patients in three groupings:

a. lung cancer patients attending the clinic,
b. newly diagnosed lung cancer patients (within six weeks of diagnosis), and
c. patients within the last three months of life.

The purpose of this study was to establish a knowledge base regarding the needs within the service in order to allow future service improvement and to answer the following question:

> *What are the supportive care needs within the lung cancer population attending the Stobhill Hospital multidisciplinary lung clinic, and are there identifiable factors which can aid service provision to meet these needs?*

It was recognised that from this study valuable lessons could be learned which might also be applicable to other settings. The author of this thesis worked within the Stobhill service and was instrumental in establishing the project. At the initial development stages, the project was intended to be a service evaluation/audit rather than formal research, and it was not to be submitted towards a higher degree. Subsequently, the possibility of completing an evaluation of supportive care needs towards a formal higher degree was raised and considered. At that time, the author was no longer employed in Stobhill but worked in Tayside.

This development process has raised issues regarding methodology and ethical status, which are addressed in Sections 3 and 12. Limitations regarding the use of instruments and clinical indices from the current practice rather than introducing new validated tools are evident; discussion follows in Section 12.

3.4 Ethics

The current study evaluated needs within the lung cancer service at one site and utilised tools and clinical indices in use within the Stobhill lung cancer clinic. The purpose of the study was to describe the prevalence of supportive care needs within this service, identify key issues to be addressed by future service developments, understand the potential role of clinical indices to target resources and evaluate current service provision.

There is no universally agreed definition of research. It can be defined as 'the attempt to derive generalisable new knowledge by addressing clearly defined questions with systematic and rigorous methods.'[185, 191] Audit can consider current practice against known standards of care or can describe issues within a service. Although the definition of audit continues to develop, the Department of Health defines clinical audit as:

> *the systematic critical analysis of the quality of clinical care, including the procedures used for diagnosis and treatment, the use of resources and the resulting outcome and quality of life for the patient.*[192]

The National Institute for Clinical Excellence defines clinical audit as:

> *a quality improvement process that seeks to improve patient care and outcomes through systematic review of care against explicit standards and the implementation of change.*[192]

A service evaluation assesses current care without judging against a set of standards.[185] Service evaluation can involve the use of an intervention such as interviews or a questionnaire to perform this evaluation.[184]

It is acknowledged within the NRES guidance that there can be challenges in clearly defining all projects as research, audit or service evaluation.[184] Furthermore, it is acknowledged that projects can fall within more than one category. Key discriminators of work being deemed research include the primary aim to derive new knowledge which is generalisable, hypothesis testing, involving the introduction of a new intervention and involving a process of systematic allocation or randomisation of patient groups.[185]

The author of the current study was instrumental in the design, introduction and implementation of the questionnaire into the clinic while working within the Stobhill lung cancer service (August 2005 – July 2006). There was no intent to undertake formalised research towards a higher degree at this time. Prior to the introduction of the questionnaire, advice was sought from the Local Research Ethics Committee (LREC) Chairperson regarding the appropriate ethical framework. It was advised that the questionnaire could be used to evaluate service and, because this was not formal research, there was no requirement for further ethical approval.

In 2007, the possibility of completing a study of supportive care needs using the questionnaire towards a formal higher degree was considered. The author of the current thesis was no longer employed in Stobhill but worked in Tayside. As such, the project was undertaken as an external worker through an honorary contract and the author did not contribute to clinical care during the period of the project. However, given the above facts, it was not clear at that time whether the project could proceed as audit/service evaluation or should be considered formal research. The National Research Ethics

Service (NRES) guidance states that researchers themselves can decide what type of study is being undertaken, but if there is doubt as to whether the work is research, audit or service evaluation, an opinion from the Chairperson of the local ethics committee should be sought.[184, 191]

The University of Dundee ethics committee advises that clinical projects should be reviewed under the National Research Ethics Service (NRES) framework and for single sites through the local NRES research ethics committee.[186] NRES guidance outlines where applications for project review should be submitted according to the nature of the study and population considerations: single site projects not involving prisoners, those who are incapacitated, medical devices or human tissue should be reviewed through the appropriate LREC.[184]

Therefore, in accordance with guidance from the University of Dundee[186] and NRES,[184] as detailed above, advice was sought from the Chairperson of the LREC. It was advised that the classification of the current study as service evaluation versus research was difficult and, as such, a full ethics submission was required.

A full ethics submission was undertaken to allow scrutiny of the project and to classify the study as formal research or audit and service evaluation. The LREC had a lengthy discussion regarding this question, considering issues including the generation of new knowledge, potential for change in practice and the potential submission of work towards a higher degree. As a result, the LREC decided that the project was considered to be audit and service evaluation (see Appendix 1). As such it was not required to have documented, fully informed consent. However, it was important to inform patients that their responses were to be used towards this study.

In keeping with the LREC decision, the current study proceeded as audit and service evaluation. Given the University of Dundee ethics committee advice[186] and the NRES guidance[184] detailed above, further formal ethical advice was not sought after receiving this considered decision from the LREC. Proceeding under this status has led to some constraints which have influenced the scope and design of this study.

3.5 Design

As outlined previously, there were several stages to the development of this study. This staged development was driven by the altered purposes of undertaking the study, including formalising the work within the current thesis. However, the main driver throughout was to evaluate supportive care issues within the Stobhill service to aid future service development.

Five main steps have been suggested for evaluating health needs.[94] Step one includes: identifying the aims of the project, defining the population of interest, establishing the resources available and understanding the risks. Step 2 includes: profiling the population, gathering data and identifying needs. Step 3 includes: delineating the key issues, understanding the determinants of the key issues and considering the actions required to meet those needs. Step 4 includes: instituting action and monitoring the effects. Finally step 5 includes: learning from the project and measuring the impact of the evaluation.

Methods of evaluation include questionnaires (or surveys), interviews, focus groups and formal research utilising purposeful sampling and randomisation. The choice of method will be determined by the aims of the project, the population of interest, the size of available sample, time available and resource constraints.[193] In considering the above issues it was decided that a questionnaire-based study best suited the aims of the project. This decision was influenced by the aims of this study and the needs of the clinical service. Integrating assessment tools within clinical practice has been previously described in mixed populations[194] and in lung cancer patients.[195] However, these dual concerns have placed limitations on the project and influenced the methodology used.

Questionnaires are well suited to gaining factual information from a large sample, thus allowing fuller representation of views from within a large population. The most common objective of survey research is 'to describe'.[193] Questionnaires are also cost-effective and compare well to the resource dependent methods of interviews and focus groups.[196, 197] In many cases a validated, previously published tool can be utilised to meet the project aims. This is not always the case, however, and questionnaires may need to be developed, or amended, to suit the specific purposes of the service in question.[193]

3.6 Sample Considerations

To obtain a range of views and ensure that the sample was representative of all patients attending the Stobhill lung cancer clinic, it was decided that all lung cancer patients attending the clinic could complete the questionnaire. Therefore, a consecutive sample of convenience was used. As this was primarily a descriptive study, no *a priori* power study was necessary.

Patients without a diagnosis of lung cancer were excluded from the study; all other patients were included. It was, therefore, expected that there would be a representation of the whole clinic population and patients at different phases within their lung cancer journey.

The primary aim of this work was a descriptive study that considered three main groupings of lung cancer patients (Section 6 and Aim 1):

1. any patient attending the multidisciplinary clinic, irrespective of phase of lung cancer journey;
2. newly diagnosed patients (those within six weeks of diagnosis);
3. patients within the last three months of life.

Responses from the first two groups were obtained by evaluating the first questionnaire completed. The final questionnaire completed within three months of death was used to evaluate needs in the third group. There was no *a priori* stratification because timing of questionnaire completion prior to death could not be predicted. However, purposeful, *post hoc* coding was applied to separate the three groups of interest for detailed analysis. New referrals to the Stobhill lung cancer service number from around 200 to 250 per year. Around 130 people are confirmed to have lung cancer each year. Therefore, in 30 months, around 325 new diagnoses could be made. Consensus discussion was undertaken to identify a reasonable time-frame for this project. Based on the referral audit data, a collection period of 30 months was thought long enough to allow adequate representation of all patients (new patients, those undergoing treatment, survivors in follow-up and those receiving supportive care), newly diagnosed patients and those within three months of death.

There was no randomisation of patients as there was no specific intervention to assign. No pilot study was undertaken prior to this study; however, previous questionnaires had

been used within the multidisciplinary clinic for clinical care in the past. From this, it was clear that the use of a questionnaire was feasible.

3.6.1 Expected Characteristics of the Sample Population

The expected characteristics of the population within the study were derived from published UK national lung cancer audit data (Table 4). It was expected that there would be a predominance of males within the sample given the higher prevalence of lung cancer in males.[3] The proportions of NSCLC and SCLC were expected to be in keeping with national figures: around 70% NSCLC and 15% SCLC.[3, 56] The majority of patients were expected to have advanced or metastatic disease and therefore surgery would not be appropriate.[3] In addition to this, it was expected that the population would be deprived, in keeping with the known economic landscape of the catchment area (Sections 1.2 and 3).

Chracteristic	Data sourced from national lung cancer audit	
Gender		
Male	53%	*
Female	47%	*
Age		
50 years and less	6.15%	
51-69	35.31%	
70 years and more	58.54%	
Histology		
NSCLC	60.90%	*
SCLC	15%	*
No/Negative histology	19.80%	*
Other	2.80%	*
Stage		
1a	3.31%	
1b	3.94%	
2a	0.55%	
2b	2.29%	
3a	4.42%	
3b	8.18%	
4	22.99%	
Unknown	45.42%	
Uncertain	8.87%	
Treatment		
Surgery	9.88%	
Chemotherapy	25.24%	
Radiotherapy	22.04%	
Palliative Care	17.61%	
Active monitoring	12.86%	
Performance status		
0	13.19%	
1	21.24%	
2	13.66%	
3	11.17%	
4	3.72%	
5	16.76%	
Missing	20.27%	

Table 4: Expected characteristics of lung cancer patients attending Stobhill multidisciplinary lung cancer clinic. UK data and Scottish data (denoted by *) presented.

3.7 The Lung Cancer Clinic Questionnaire

The Lung Cancer Clinic Questionnaires (LCQ, Appendix 3) contain version 1 of POS (see Appendix 4) with some adaptations to suit the clinic environment. To meet the primary aim and secondary aims (see Section 2), further questions have also been added to record information related to service use, performance status, satisfaction, preferences regarding follow-up and understanding of current clinical structure.

There are several different tools available to allow evaluation of symptoms[183] and supportive care needs[149] in cancer patients. Commonly used tools include: The

European Organization for Research and Treatment of Cancer Core 30-Item Quality-of-Life Questionnaire (EORTCQLQ-C30),[198] Functional Assessment of Cancer Therapy-General (FACT-G)[199] questionnaire, the Edmonton Symptom Assessment Scale (ESAS)[200] and Symptom Distress Scale (SDS).[201] Some instruments have been particularly focused on lung cancer patients.[195] These include theLung Cancer Symptom Scale (LCSS)[202] and the lung cancer-specific subscales of the FACT questionnaire and EORTC Lung Cancer 13-item (EORTC-QLQ-LC13[203]) questionnaires.

A systematic review of cancer symptom assessment tools has recently been published by Kirkova et al.[183] They reviewed 21 instruments used in cancer symptom assessment and found a great deal of variety in the tools available. The number and type of symptoms evaluated varied but usually included pain, fatigue and anorexia. Across all of the tools evaluating five or more symptoms, 56 different symptoms or issues were part of the assessment. The tools may assess occurrence, severity or duration. They may also assess 'global distress' or individual 'symptom distress'. Time frames also vary between tools from 'symptoms now' to 'symptoms over weeks'. Other dimensions such as practicality, validity and reliability were assessed for selected tools. No single tool was felt to be ideal, but the authors noted that a balance must be struck between comprehensiveness and patient compliance.

This balance becomes more difficult as the patient's performance status worsens and fatigue increases. It is noted that when reporting symptom prevalence, it is important to remember the filter effect that a list of symptoms will have, and that if a proxy is required to help complete the questionnaire, the assessment may be affected. The authors noted that although validated instruments provide reliability (when applied to a sample that is homogenous with the validation population), comprehensive non-validated tools also contribute to knowledge regarding prevalence of symptoms and symptom distress. The choice of instrument relates to consideration of the purpose of research, targeted symptoms and the suitability to the clinical setting it is deployed within.[183]

3.7.1 Patient-Reported Outcome Measures

Outcomes can be described in terms of 'achievement or failure to achieve desired goals'.[204] Patient-reported outcomes (PROs) can be defined as 'a measurement of any aspect of a patient's health status that comes directly from the patient (i.e. without the

interpretation of the patient's responses by a physician or anyone else)'.[205] This definition can include information gained through measurement, but some extend it to include the development of the tool (i.e. contents, style and goals) being used to gain information.[206]

PROs are now being integrated into clinical trials as primary and secondary end points and into routine clinical practice. PROs can be measured using one of the many and varied 'patient reported outcome measures' (PROMs). In 2006, the Food and Drug Administration (FDA) in the USA issued draft guidance on the use of PROMs in drug development and trials.[205] Within the UK it has been said that 'patient choice over treatment and care is a central feature of the NHS'. As part of delivering 'patient-centred care',[207] the UK government is developing the use of PROMs to promote this feature.[208]

PROMs may be generic or disease-specific and utilise a variety of response mechanisms. They may assess global outcomes or specific domains and include tools for symptom assessment, quality of life assessment, satisfaction scores, health assessment and adherence to treatment assessment (Table 5).

Outcome Domains	Types of outcomes measured
Communication	Patient-provider communication
Decision Satisfaction	Patient involvement in decision-making Patient-provider concordance Patient decisional conflict
Patient Attitudes and Behaviours	Patient self-efficacy Patient adherence Patient behaviour change
Provider Attitude and Behaviours	Provider recognition of patient problems Provider management of patient conditions
Satisfaction	Patient satisfaction
Health Status	Patient health status Patient quality of life
Resource Use	Patient resource use Visit length

Table 5: Types of patient-reported outcome measures in seven domains. Modified from 'Patient involvement and collaboration in shared decision-making'.[209]

It is proposed that PROMs can be used in routine clinical practice to help prioritise problems, facilitate communication, identify hidden problems, elicit preferences, monitor changes in disease, monitor responses (or lack thereof) to treatment and to train new staff.[210] PROMs have also been developed to aid the appropriate and timely referral of patients from one service to another (e.g. SPARC[153]). Greenhalgh et al[206, 211]

critiqued the use of PROMs and questioned the methods by which they are being evaluated. Noting systematic reviews, Greenhalgh et al[206, 211] questioned the real impact of PROMs in changing practice or on decision-making; they propose studies not only assess *if* a tool can be used to promote change but also *how* the process occurs. (i.e. the factors behind the change including if the study affected these)

Detmar et al[212] studied the preferences of patients undergoing palliative chemotherapy (n=273) with regard to discussing quality of life issues with their doctor. They found that most patients wished to discuss physical symptoms (90.2%) and physical functioning (81.7%), but less wished to discuss emotional (67.4%), social functioning (44.3%) and family issues (52.7%). In contrast, 6.2% specifically did not wish to discuss emotional issues, 18.1% did not wish to discuss social functioning and 18.7% did not wish to discuss issues related to family. Many patients would only discuss issues if the discussion was initiated by the doctor (emotional (26.4%), social (36.6%) and family (28.6%)).

Higginson and Carr,[210] however, assert that PROMs do not replace all other clinical assessment but can operate alongside. In lung cancer, assessment of physical symptoms is routine but psychosocial burden is poorly assessed.[11] Given that many patients would discuss such issues *if* they were raised by the health care team, PROMs may facilitate recognition of problems and promote discussion or action if the patient desires further support.

The Palliative Outcome Scale (POS) was developed by Higginson and Hearn in response to a lack of tools which were suitable to identify supportive care needs in patients referred to palliative care and to be usable within the clinical environment.[147] Within the Stobhill lung cancer service, palliative care plays an active part of supportive care provision. Although POS has not been specifically validated in lung cancer patients, it has been validated in various settings including hospital, hospice and out-patients.[147, 213-215]

The clinical utility of this tool across settings, its low time and energy burden within the clinical setting and its ability to assess a variety of domains within supportive care led to its selection. The characteristics of the above tools have been tabulated in Table 6.

				Domains evaluated		
Instrument	Item number	Validated	Lung cancer specific	Physical	Psychological	Social
EORTC QLQ-C30, LC13	43 in total	Yes	Lung module	Yes	Yes	Yes
FACT-L	36 in total	Yes	Lung module	Yes	Yes	Yes
LCSS	9	Yes	Yes	Yes	Yes	Yes
ESAS	10	Yes	No	Yes	Yes	No
SDS	13	Yes	No	Yes	No	No
POS	12	Yes	No	Yes	Yes	Yes

Table 6: Summary of assessment tools including the Palliative Outcome Scale.

3.7.2 Development of the Lung Multidisciplinary Clinic Questionnaire

The questionnaire used was developed to identify supportive care needs and determine patients' views of the service. The basis of the questionnaire was the Palliative Outcome Scale, version 1 (Appendix 4). The POS was chosen as it evaluates all domains of interest, physical symptoms, psychological needs, social concerns and service use. Furthermore, POS readily identifies unmet psychosocial and practical needs. This was of importance as needs in these domains are poorly identified and managed in lung cancer clinics.[11-13]

This tool is short and readily integrated within a busy clinic environment. As such, it is ideal for the dual purpose of identifying individual need in real time and providing population information for service development. This wish to keep questionnaire burden low and enable clinical practice to utilise individual information in real time was the main driver behind the choice of POS and the decision to adapt this tool rather than use a battery of validated tools. The Palliative Outcome Scale is described in Section 3.7.

It could be argued that a battery of detailed tools would give greater information and increased validity to the scope of this study. However, it is of note that in one such study of supportive care needs in lung cancer patients, Sanders et al[216] conclude that they identified no useful tools for the clinical setting. This conclusion was based on the fact that the battery of questionnaires to assess supportive care needs, quality of life, function, psychological symptoms and coping mechanisms would not be suitable for the clinical setting given the time and resources required to use them.

3.7.2.1 The Palliative Outcome Scale

Outcomes have been described in terms of achievement or failure to achieve desired goals.[204] Hearn and Higginson[204] reviewed clinical tools available for measuring

supportive care outcomes suitable for a palliative population.[213] They evaluated the specific areas of: Quality of life (QOL), symptom control (both physical and psychological) and family support. Twelve tools were identified as being designed for those with advanced cancer, providing a multidimensional assessment and not specific to only one cancer type. Although each tool reviewed fulfilled palliative objectives in part, none fully met all the criteria set.[204]

From this background, the Palliative Outcome Scale (POS) was developed and validated in patients with advanced cancer in a variety of settings including outpatients, the community setting and in-patient hospice units.[147] Further experience with POS has been obtained in a variety of settings and POS has been found to be adaptable and acceptable to patients.[213, 217, 218] It has been translated into several different languages (German,[219] Italian, Spanish,[220] Portuguese, Urdu, Punjabi, Swahili and Chinese).[213] The majority of these studies have utilised version 1 of the POS. Using both the German and Spanish translations, anxiety perceived in the support network remained the most prevalent 'severe' issue.[219, 220]

POS has also been adapted to assess supportive care needs in patients with motor neurone disease (MND).[217] In contrast to the cancer studies, information needs rated much higher than personal or family anxieties in this small study of patients with MND. There has also been some recent work in developing a non-validated symptom assessment 'bolt-on' for POS, which has been used to assess symptom burden in patients with chronic kidney disease.[221] Although POS is copyrighted, it can be used freely and use can be registered with Professor Irene Higginson and the POS Development Team, King's College London, UK[222, 223] (Appendix 2).

POS allows individual item information to be gained about physical symptoms, psychological issues, spiritual considerations, practical concerns, emotional concerns (the patient's and the patient's perception of their family's) and psychosocial needs (personal and familial).[213] It defines the presence of each of these through a series of questions and asks the patient to rate the impact of the issue on their lives. In total, there are 12 questions within POS. Ten questions ask about how the individual perceives the effects of physical, psychosocial and practical issues over the previous three days.

The patient can rate the effect of the item on daily life on a five point Likert scale ranging from 'none' (0) to 'overwhelming' (4) (i.e. the higher the score, the greater the supportive care need burden). A further question asks for free text of what are the 'main problems'. POS has been designed to allow self-completion, assisted completion or proxy completion to occur, dependent on any individual's ability to fill out the form. The final question records how the questionnaire was completed (i.e. self-completed, help from family or help from staff).

There is no suggested way to categorise POS responses, and different approaches have previously been taken. The tool developers have utilised analysis of severe symptoms (classified as either 'severe' or 'overwhelming'),[147] and other authors have utilised categories of 'moderate to severe' (including moderate, severe and overwhelming).[218] There is wide variation on reporting of symptoms in the literature with both means and medians being utilised. In addition to single item analysis, a summary score from the initial ten questions can be calculated ranging from to 0-40.

A 'staff' version of POS has also been developed with an additional question assessing Eastern Cooperative Oncology Group (ECOG) PS. The two questionnaires can be used together to add mapping of supportive care needs over time and allow 'proxy' assessment to continue on from a known baseline if the patient becomes unable to complete the forms. Development of this patient reported outcome measure has involved patients' views. Initial questions were constructed based on the previously available tools, utilising the most reliable and valid forms of questioning to cover the desired assessment domains. After a consensus panel (including a patient representative) development phase, the initial tool was piloted with 25 individuals. Further revisions were made in accordance with the findings of this study. Version 1 of POS was then evaluated in a multi-centre, prospective study of 450 patients with advanced cancer.[147] This study demonstrated that the tool was appropriate for in-patient and out-patient clinical settings with a maximum of ten minutes being required to complete the form. Content was found to be valid, yielding information relevant to palliative and supportive care needs and not exploring irrelevant issues. Some staff noted that the tool could promote discussion of certain topics or aid raising a subject that may have otherwise remained hidden. In one centre there was concern the question relating to 'Is life-worthwhile?' may have caused distress in two patients and could be difficult to ask. Other centres found this question helpful.

Patient interviews assessed face validity (an evaluation by experts or selected patients whether the tool makes sense) and found a general acceptance that questions were appropriate and there were no missing issues. Most of the patients interviewed (9/12) felt it would be useful for staff to know the information yielded from POS. Two of the twelve felt care was at a good level and that additional information was not required. Comparison of staff rated responses and patient-rated responses revealed good levels of agreement (Cohen's Κ) and correlation (Spearman correlation) for the majority of items. Furthermore, the proportion of items scored within one point of each other between patient and staff completed questionnaires was high (in 7/10 items, ≥80% of responses were within one point). Test/re-test reliability was high with 9/10 items having more than 80% of patients within one score of matching. The α reliability co-efficient for patient-rated scores was 0.65. POS was able to respond over time to improvements for all but the item relating to 'have you been able to share how you are feeling with family or friends?' These improvements were only statistically significant for patient-reported pain and patient perception of family anxiety. It was noted some items were rarely rated severe (e.g. time wasted and 'are your personal affairs up-to-date'). The authors commented that a 'floor' effect may have been observed with such items (i.e. no further improvement was possible). The main issues raised in the free text section were: dyspnoea, weakness, tiredness, nausea and poor appetite.

POS was further evaluated by Stevens et al[218] in a specialist cancer centre, assessing patients' needs at referral to a palliative care service and one week after. They were able to demonstrate the clinical usefulness of the tool, improved outcomes at one week and the acceptability of POS to patients. Again, in this study, the level of perceived family anxiety was rated higher than any other item. Adaptation of POS has occurred in a variety of clinical settings to reflect local environment and needs. The development team note that in non-specialist palliative care settings the title has been changed to Patient Outcome Scale to avoid any patient anxiety or distress related to the word 'palliative'.

A second version of POS has been developed, with two further alterations:[222]

- Question 7 has been changed from 'have you felt life was worthwhile' to 'have you been feeling depressed'.
- A trigger advising patients to visit their GP was added if their response indicated 'severe' or 'overwhelming' depression.

If it is felt that the 'worthwhile' question could cause patients distress, then the second version can be used. The trigger prompts patients with severe depression to seek help. The developers of the Palliative Outcome Scale note that that version 2 is particularly suited to those people with supportive care needs who have a chronic or progressive disorder.[222]

As lower QOL and higher symptom burden may be associated with poorer survival,[119, 224] POS may serve the dual purpose of identifying supportive and palliative care needs of lung cancer patients in the hospital setting and aiding prognostication.

3.7.2.2 The Palliative Outcome Scale and Lung Cancer

Eighty-six patients (19.6%, n=450) taking part in the development study for POS had a diagnosis of 'respiratory tract' cancer.[147] In a subsequent study comparing POS with two other outcome measures, 22 (18.5%) further lung cancer patients participated in that evaluation.[215] In another small study (n=30), three more lung cancer patients were studied using POS.[218] However, this tool has not been studied in detail in ambulatory lung cancer patients within a hospital outpatient setting.

3.7.2.3 Modifications to the Palliative Outcome Scale and Choice of Version One

The developers of POS recognised that different services may need to adapt the tool to suit the local need.[213] It is of note that such adaptations of POS have been reported in its use in patients with motor neurone disease[214] and in patients with renal disease.[221] In these studies the tool was not validated further but the adaptations were made to suit the aim of understanding need prevalence in specific conditions. It has been noted by the authors themselves[147] that POS does not allow the detailed assessment of a full range of symptoms. Versions 1 and 2 specifically ask only about the effects of 'pain' and then one further question for 'other' symptoms. No other physical symptoms are addressed.

Version 1 of POS has been used in this study since the population under evaluation did not suffer from chronic progressive disorders. In addition, no 'trigger to seek advice' was necessary relating to depression questions. Each patient was being reviewed at clinic at time of questionnaire completion, and any symptom or concern that was severe could be addressed at that time.

Rather than focusing on 'depression' specifically, the question of 'do you feel life is worthwhile' covers aspects of depression but also adds a wider insight into patients' own views of the value or worth of life. Patients may not *feel* depressed but may *consider* life of little worth. Furthermore, anxiety has been noted to be a key issue in all previous studies utilising POS. Low self-esteem has been postulated as having a key role in development of maladaptive anxiety. Therefore, inclusion of the question regarding self-esteem was thought to be important, allowing some evaluation of this specific component of psychological distress.

The Palliative Outcome Scale asks each patient to consider items 'over the past three days'. Lung cancer is a dynamic condition with an often rapidly progressing clinical picture.[56] However, it was intended to evaluate supportive care needs within the outpatient population rather than identify acute issues. Furthermore, in the out-patient setting review intervals are often in weeks or months. Through consensus discussion it was decided that the 'three days' period should be adapted to consideration of a longer period. Thus, each question was adapted to consider 'over the past four weeks ….'

In keeping with other users of POS,[213] it was considered using the word 'palliative' in the questionnaire title was inappropriate for a population of patients containing a wide range of cancer journey stages. As some patients attending the clinic had mesothelioma and some had not been diagnosed with lung cancer, the word 'cancer' was not used in the title. The title 'Lung Multidisciplinary Clinic Questionnaire' was therefore used instead of POS.

3.7.3 Additional Questions and Domains within the Lung Cancer Clinic Questionnaire

As outlined above, additional questions were incorporated within the Lung Cancer Clinic Questionnaire to allow a single instrument to be used. The additional questions are outlined below.

3.7.3.1 Physical Symptoms and Function

In keeping with the approach by Murphy et al,[221] specific questions relating to lung cancer were added to allow identification of these symptoms. This was limited to three physical symptoms of key clinical relevance: dyspnoea, cough and haemoptysis.

Three new questions were framed in the POS style to address these three major respiratory symptoms:

- Over the past 4 weeks, have you been affected by shortness of breath?
- Over the past 4 weeks, have you been affected by cough?
- Over the past 4 weeks, have you been affected by coughing up blood?

These could be responded to individually in the same way as POS assesses pain and 'other' symptoms:

- Not at all, no effect
- Slightly – but not bothered to be rid of it
- Moderately – 'symptom' limits some activity
- Severely – activities or concentration markedly affected
- Overwhelmingly – unable to think of anything else

It could be argued that further symptoms of relevance could have been added, including fatigue, anorexia and others. Again, the questionnaire performing a useful clinical role for individuals was balanced against the aim of understanding the needs of the population. Furthermore, it was recognised that POS allows patients to identify any other main symptom of relevance under the 'other symptoms' item.

The Eastern Cooperative Oncology Group (ECOG) Performance Status (PS) is used within the Stobhill cancer service to aid decision making. This is a widely used scale in lung cancer management and its use is advised and integrated within the major British guidelines.[10, 67] This scale has been critiqued regarding its ability to assess function in the elderly and may overestimate fitness for therapy.[225, 226] This is of particular relevance when considering palliative treatments for conditions in patients who may die *with* their cancer rather than *of* their cancer. In lung cancer the median survival is such that the vast majority of patients will die *of* their cancer.[227] Furthermore, under-treatment of elderly patients with lung cancer is well documented.[227, 228] Indeed, the ECOG PS has been well validated as one of the main determinants of fitness for therapy and prognosis[100] in lung cancer[10], a disease predominately affecting elderly patients.[3] Patient-rated ECOG PS has been shown to be a better prognostic guide in lung cancer patients than the Karnofsky Performance Status (KPS) Scale.[103] ECOG PS is readily used within a busy clinical environment and this consideration often takes precedence over utilising longer study methods that may provide more subtle information relating to function.

In the patient version of POS, there is no self-assessment of PS; within the staff version of POS, PS can be assessed by proxy. It is known that assessment of PS can vary between patient self-rated, nurse-rated and doctor-rated PS.[229] The ECOG scores functional status from normal '0' to dead '5'. Clearly patients could not be asked to report a score of 5 to this question. In keeping with the staff version of POS, a question asking patients to report PS was included. The 0-4 Likert scale component of ECOG PS is similar to the POS style of question. In keeping with the intention to assess needs over time rather than acute events, patients were asked to assess their own PS 'over the past four weeks'.

3.7.3.2 Service Usage and Preferences

To meet Aim 5, data regarding patients' service usage was included in the LCQ. The occurrence of 'new or changing' symptoms since the last clinic review was evaluated with an additional question (Have you experienced any new or worsening symptoms since last being at clinic?) asking for a yes or no answer.

The length of time since the previous attendance was estimated by the patient themselves as: first appointment, less than four weeks, four to eight weeks, two to four months or greater than four months. Actual interval times could be calculated from date of completion of the questionnaire.

Attendance at the general practitioner within the clinic interval could be rated as 'yes' or 'no', and free text allowed patients to indicate the reasons for attendance.

The British Thoracic Society (BTS) guidelines of lung cancer management state that 'it should be clear to patients who their supervising consultant is'.[69] This was audited, allowing patients to pick one main person from general practitioner, respiratory consultant, oncologist, surgeon, palliative care consultant, specialist nurse, uncertain and other in response to the question:

- Who do you think is the main person in overall charge of your care?

There is a paucity of evidence regarding patients' preferences for follow-up care. In keeping with Aim 5 to gain information regarding the follow-up preference of patients, the following question was posed:

- How would you prefer your on-going follow-up to be organised?

The choice of responses reflected the different models of care that have been described in the literature:

- Regular, routine appointments at this clinic even if you have no new or changing symptoms.
- If new or changing symptoms develop then an arranged, rapid return to this clinic through your own GP.
- By a hospital-based specialist nurse-led service with return to this clinic only if there are new issues to be assessed.

One question assesses the patient's perception of the number of health care professionals involved in their care:

- Do you feel you are seeing too many different health care professionals? ('Yes' or 'No').

3.7.3.3 Satisfaction with Service

In keeping with the Scottish Government's plan for 'Better Health, Better Care 2007',[230] there was a desire to determine patient satisfaction with the Stobhill lung cancer service. This was discussed as an additional outcome at the end of year 1 of the study. To achieve a survey of patient satisfaction without further instrumental burden on patients, the Lung Cancer Clinic Questionnaire was further modified to enable evaluation of this. Three satisfaction questions were added in years 2 and3. These questions were sourced from work previously carried out at Stobhill Hospital to develop a patient satisfaction questionnaire (PSQ).[231] Although this has conferred further methodological issues, it did enable a single tool to be used, thus maintaining ease and speed of use.

The measurement of satisfaction with services is in keeping with the desire to provide high quality, patient-centred care. However, there are issues surrounding this area of evaluation well described in the literature.[232-238] Fundamental to these issues is the lack of an accepted definition of 'satisfaction'[236] and how it relates to patients' real views of the quality of care provision.[239] One definition that has been offered states satisfaction is 'a recipient's reaction to salient aspects of the context, process and result of the service

experience'. The reaction can be considered in cognitive, emotional and affective terms.[236]

The need to understand the concept of satisfaction and to ground that concept within a strong theoretical framework before it can be applied to understanding what factors relate to it has been outlined by Linder-Pelz.[240] Starting from this basis may reduce the heterogeneity in approaches taken to measure this patient-rated outcome. Turris[239] further critiques the concept and suggests that satisfaction can be seen as a symptom of patients' interaction with quality rather than the underlying array of interactions. It is also not clear how often patients themselves would choose to assess a service in terms of satisfaction.[236] When asked to do this, patients often rate satisfaction high. This may represent a bias towards trying to please healthcare professionals, wishing not to complain or worrying that any service rated with low satisfaction may be withdrawn.[240, 241]

One model of satisfaction evaluation attempts to address some of these issues by placing value on responses that indicate dissatisfaction. This 'discrepancy' model[242] has some advantages within the healthcare environment where biases such as 'gratitude' strongly skew responses towards the positive.[241] The results from this study will be reviewed in the context of these issues.

The questions incorporated within the LCQ were sourced from work previously carried out at Stobhill Hospital developing a validated patient satisfaction questionnaire (PSQ).[231] The PSQ demonstrated good internal consistency (Cronbach's α=0.93) and test/re-test reliability. Overall, in this group of newly diagnosed lung cancer patients, high satisfaction was found. There was a strong correlation between satisfaction scores and symptom scores from a concurrent symptom assessment score.[231]

- How satisfied were you with the way tests were carried out *(taking into account time taken, discomfort and side effects)*?
- How satisfied were you with the way in which you were told what was wrong?
- How satisfied are you with the way in which you are being followed up at the hospital clinic?

Patients were asked to respond in a POS style:

- Very satisfied
- Satisfied
- Unsatisfied
- Very unsatisfied Main reason:_____

Responses were scored from 'very satisfied' (0) to 'very unsatisfied' (4), and a summary satisfaction score (0-12) was calculated, with higher scores representing lower satisfaction.

This further adaptation to the LCQ may have influenced responses; therefore, comparisons of responses from year 1 and years 2/3 were completed to evaluate for differences.

3.7.4 Timing of Questionnaires

The timing of questionnaires was determined by their use in clinical practice. Patients could complete a questionnaire on any visit to the lung cancer clinic; therefore, no specific interval or timing was enforced in this study. To include evaluating the needs of lung cancer patients within the last three months of life, retrospective coding was required. Clearly this could only be determined after death had occurred. Therefore, patients could complete as many questionnaires as attendances in the clinic up until death. Retrospective coding was then applied to allow identification of the final questionnaire completed within three months of death. The detailed timing of the questionnaire response is outlined in Section 6.1.2.

3.7.5 Distribution and Collection of Questionnaires

The questionnaire was integrated into the routine clinical practice being offered to each patient when they were weighed on arrival. Demographics and weight were also recorded on the form. Patients could then complete the LCQ while waiting for review.
Patients were informed that completion of the questionnaire would contribute to service evaluation but they were not required to complete the LCQ. Furthermore, their care would not be influenced if they chose not to complete the questionnaire. The LCQ was headed with a statement informing the patient that their responses would be used to improve their care and would be further analysed to develop service and help in the care of others (Appendix 3). The content of this header was reviewed by the LREC during the ethics submission. No further patient information leaflets were deemed necessary and signed consent was not required. Translators were available through the normal clinic mechanisms and forms could be completed by the patient alone, with help from family/friends or with help from clinic staff.

Completed questionnaires were returned to the nurse when they called each patient through for their appointment. The LCQ then accompanied the patient's notes into the clinic review. As such, the clinician was able to use the tool and identify any individual's needs that had been recorded. If any action was required from the responses, this could be initiated. The lung cancer specialist nurse was in attendance at the clinic and could also respond to identified needs. After the clinic, forms were stored over a period of four to six weeks and then collected by the author who had no input into the clinical setting.

3.8 Data Retrieval and Collation of Questionnaires

Patient responses to each of the LCQ questions were entered into a purpose designed spreadsheet using Microsoft® Office Excel 2003. Medical case notes were obtained with at least one month interval from date of questionnaire completion (to allow processing of clinic visit and treatment decisions to occur). Information obtained from review of the medical case notes was entered into the spreadsheet to record: patient number, LCQ number, gender, age, postcode, histology, stage, date of diagnosis, treatment recommended, treatment given, summary POS score, item POS scores, respiratory symptom summary score, respiratory symptom item scores, satisfaction summary score, satisfaction item scores, all other of LCQ item scores, PS at diagnosis (assessed by doctor), current PS (rated by patient), weight at diagnosis, current weight, date of clinic and documented involvement of palliative care services. Number of days from diagnosis to date of LCQ completion was calculated by subtracting diagnosis date from LCQ completion date. Postcodes were used to obtain Carstairs deprivation category and decile for each patient as established at the last Scottish census in 2001.[48] The spreadsheet was anonymised and password protected.

3.9 Mortality Data

Mortality data was obtained at six monthly intervals throughout the 30 month collection period. The initial search was performed by Stobhill Information Services (SIS). The SIS search utilises postcode, date of birth and hospital number to identify any deaths within the North Glasgow area. The register confirms vital status as 'dead' but does not give cause of death. Most deaths occurring would have been notified to North Glasgow Hospital Trust and included within this register. However, some deaths may not have been recorded on this register. A second, confirmatory search was performed utilising

the general register office for Scotland's 'Statutory Death Search'. All registered deaths within Scotland can be identified via this database and the death certificate can be reviewed to establish cause of death.[243] The following search strategy was used to cross check vital status, dates of death and establish cause of death:

- Surname
- Surname with 'Soundex*' function.
- Year range of death: 2005-2009
- Birth year +/- 3 years

**Soundex is a widely used indexing phonetic algorithm. It allows archiving of names by sound, as pronounced in English. Names with the same pronunciation can be encoded to the same representation allowing them to be matched despite minor differences in spelling.*[244]

Date of death and cause of death was recorded in the spreadsheet, allowing calculation of survival to death (or censor) from diagnosis and survival to death (or censor) from date of LCQ completion or diagnosis.

3.10 Further Ethical Considerations

Researching and completing service evaluations with patients who have advanced cancer or are near to the end of life demands consideration of several ethical issues.[184, 193, 245, 246] Despite the challenges, it has been argued that research and service evaluation are part of good holistic care and that vulnerable patient groups should not be denied the benefits from research participation.[247] Furthermore, many patients, including those with cancer and short prognosis, are keen to be involved in research.[248, 249] Patients may participate through altruism, for personal gain or to gain an increased sense of meaning.[249]

Informed and valid consent is necessary when engaging in research.[245] This study was a service evaluation/clinical audit and, as such, did not require documented, informed consent. Guidance regarding this issue and an overall assessment was sought from and provided by the LREC and its Chairperson. However, it was important to ensure that patients understood that the questionnaire was part of a project, that responses would be analysed and that they were not required to complete the form. This was achieved as outlined above (Section 3.7.5).

Although many patients do wish to take part in research, some may not. One difficulty in conducting evaluations within a clinical service is that patients can feel obliged or

coerced to take part.[193] This could have implications both for the provision of service for patients and for the reliability of information provided. It needs to be clear that clinical care is not dependent on participation. In any project that engages with patients over the course of time, the understanding that participation remains the individual patient's choice should be continually recognised.[245]

It is also important to maintain the confidentiality of participants in any project. This can be achieved though anonymising data and ensuring password protection of data (Section 3.8).

Although benefits can be gained through participation in research, it is also important to minimise any potential harm or distress. This includes considered wording of questions within surveys and interviews, providing support structures are in place to deal with issues raised and being mindful of this throughout any work. In this study, the nurses within the lung cancer clinic played a pivotal role in providing support to patients, the questionnaires were viewed within the clinic setting (and issues raised could be addressed) and the lung cancer nurse specialist was available for additional support provision.

In dealing with the ethical issues surrounding working with vulnerable populations, it is wise to gain adequate supervision, follow the available guidance and seek advice from an experienced ethics committee during any project, as was done in this study (Section 3.4 and Appendix 1).[193]

3.11 Statistical Analysis

Statistical analysis was carried out using SPSS™ Version 17.0. Data analysis was conducted in four phases:

- coding,
- descriptive analysis of prevalences and percentage responses to Lung Cancer Clinic Questionnaire items,
- univariate analysis to identify associations with key issues and
- multivariate analyses to identify independent predictors of key issues.

3.11.1 Coding

To enable analysis of the three groups of interest, coding was applied to the data. The Microsoft® Office Excel 2003 spreadsheet data was imported into SPSS™ Version 17.0. Coding identified patient number, first completed questionnaire (Q1), subsequent questionnaires (QX, where X=number of questionnaire) and 'final' questionnaire (QF). The final questionnaires were also separately coded to allow identification of when a patient had only completed a single questionnaire (i.e. when Q1=QF). Further coding facilitated separation of groups from within the data including: histology, stage of disease, presence or absence of metastases, age groups, POS scores, respiratory scores, satisfaction score, performance status, time from diagnosis to LCQ completion (allowing newly diagnosed patients to be identified), time from LCQ to death (allowing QF completed in last three months of life to be identified), percentage weight change from diagnosis to LCQ completion and certain/uncertain of who is in charge of care.

3.11.2 Descriptive Analysis

There is no suggested way to categorise POS responses, and different approaches have previously been taken. The tool developers have utilised analysis of severe symptoms (classified as either 'severe' or 'overwhelming'),[147] and other authors have utilised categories of 'moderate to severe' (including moderate, severe and overwhelming).[218] There is wide variation on reporting of symptoms in the literature with both means and medians being utilised. In addition to single item analysis, a summary score from the initial ten questions can be calculated ranging from to 0-40. Therefore, mean (SD) and median (range) were both reported in this study. Proportions were reported with confidence intervals.

3.11.2.1 Population Characteristics

Demographic and patient characteristic data is reported using proportions, means (SD) and medians (range). Overall median survival from diagnosis was calculated using Kaplan-Meier survival curves. This is compared to expected population characteristics as identified from the national lung cancer audit.[3]

3.11.2.2 Description of Supportive Care Needs and Lung Cancer Clinic Questionnaire Responses

Supportive care need prevalences as measured by POS are reported using proportions, means (SD) and medians (range) in keeping with the variable methods of reporting within the literature. Descriptive data were tabulated and graphed. Tabulated data includes missing data and graphs exclude missing data. Stacked bar charts are used to present Palliative Outcome Scale data and PS. Individual bar charts present non-POS responses from the LCQ. Although the validity of the Palliative Outcome Scale was reduced by adaptation and incorporation within the LCQ, the responses are compared to previous POS studies.

3.11.3 Evaluation of Predictors of Increased Supportive Care Needs as Measured by POS

Comparisons across higher and lower supportive care needs (POS<10 and POS≥10) were completed. The point of dichotomy was determined by distribution analysis of mean POS scores.

Categorical comparisons were made using X^2 testing for greater than 2x2 comparisons and Fisher's exact testing when considering a 2x2 contingency table. For continuous variables, unpaired Student's t tests (when normal distribution) or Mann-Whitney U tests (when non-parametric) were used. Correlations were assessed using Pearson or Spearman correlation tests depending on distribution (Appendix 8).

Multivariate analyses were performed using backwards logistic regression. Backwards logistical regression was chosen as this made no assumptions about the distribution of the data, allowed calculation of odds ratios, was suitable for exploratory analysis of outcomes and allowed independent effects to be identified. Backwards logistical regression is less likely to produce suppressor effects than a forwards stepwise model (Appendix 8).

Factors were included if $p<0.05$ and removed if $p\geq0.05$. As such, only statistically significant factors were included in the final model. This final model was assessed for goodness of fit utilising Hosmer-Lemeshow testing; non-significant values indicate the model is a good fit and the null hypothesis is accepted (i.e. there is no significant difference between observed and model-predicted values). The predictive success of the

model was compared to the null model and the effect size was evaluated using Nagelkerke's R^2 value. The ten individual POS items were then explored for direction and strength of possible correlation with the identified independent associations with higher supportive care.

Utilising the coding described above (Section 3.11), this was repeated for each of the three groupings: all patients attending the lung cancer clinic, newly diagnosed patients and patients who died within three months of LCQ completion.

3.11.4 Evaluation of Predictors of Reduced Survival from LCQ

Survival analyses were carried out using Kaplan-Meier survival curves, log rank comparisons and Cox regression techniques.

Kaplan-Meier survival curves were calculated for survival in days from date of LCQ completion to death or censor. Survival was evaluated as time from completion of LCQ until date of death or censor. A median survival from LCQ completion was calculated with 95% confidence intervals.

Comparisons of factors affecting survival were completed by comparing differences in survival across variables of interest including a dichotomised POS score. Comparison of survival curves was carried out using log rank testing in SPSS. Factors were considered statistically significant for $p<0.05$. Those of clinical relevance and those identified in previous studies as of potential importance were then analysed by multivariate, backwards Cox regression. Factors were included if $p <0.05$ and removed if $p\geq0.05$. Only statistically significant factors were included in the final model.

Utilising the coding described above (Section 3.11), this was repeated for each of the three groupings: all patients attending the lung cancer clinic, newly diagnosed patients and patients who died within three months of LCQ completion.

3.11.5 Evaluation of Predictors of Increased Anxiety

Three main questions regarding anxiety and sharing of feelings are asked within POS:

Question 1: Over the past four weeks, have you been feeling anxious or worried about your illness or treatment?

Question 2: Over the past four weeks, have any of your family or friends been anxious or worried about you?

Question 3: Over the past four weeks, have you been able to share how you are feeling with your family or friends?

Each of these questions can be answered from 0-4 ('0' indicating no anxiety or feeling able to share and '4' indicating preoccupation with worry or not being able to share with anyone).

POS responses were compared between patients who felt lower anxiety (0-1) and those who felt higher anxiety (2-4), and patients who perceived higher anxiety (2-4) within their carers and those who perceived lower anxiety (0-1). (Pearson chi squared testing was used for categorical data if larger than 2x2 tables, two-tailed Fisher's exact test for 2x2 tables and Mann-Whitney U test for non-parametric, continuous variables.)

Statistically significant factors ($p<0.05$), those of clinical relevance and those identified in previous studies as of potential importance were then analysed by multivariate, backwards logistic regression. Factors were included if $p<0.05$ and removed if $p\geq0.05$. Only statistically significant factors were included in the final model. This final model was assessed for goodness of fit utilising Hosmer-Lemeshow testing in which non-significant values indicate the model is a good fit (i.e. the null hypothesis that there is no difference between observed and model-predicted values is accepted). The predictive success of the model was compared to the null model and the effect size was evaluated using Nagelkerke's R^2 value.

Utilising the coding described above (Section 3.11), this was repeated for each of the three groupings: all patients attending the lung cancer clinic, newly diagnosed patients and patients who died within three months of LCQ completion.

3.11.6 Evaluation of Predictors of Increased Pain

One main question regarding pain is asked within POS: Over the past four weeks, have you been affected by pain?

- Not at all, no effect
- Slightly – but not bothered to be rid of it
- Moderately – pain limits some activity
- Severely – activities or concentration markedly affected

- Overwhelmingly – unable to think of anything else

The question can be answered from 0-4 (‘0’ being no pain and ‘4’ being overwhelmed by pain).

LCQ responses and other factors were compared between patients who scored lower pain (0-1) and those who felt higher pain (2-4). (Pearson chi squared testing was used for categorical data if larger than 2x2 tables and two-tailed Fisher’s exact test for 2x2 tables).

Statistically significant factors ($p<0.05$), those of clinical relevance and those identified in previous studies as of potential importance were then analysed by multivariate backwards logistic regression. Factors were included if $p<0.05$ and removed if $p\geq0.05$. Only statistically significant factors were included in the final model. This final model was assessed for goodness of fit utilising Hosmer-Lemeshow testing; non-significant values indicate the model is a good fit and the null hypothesis is accepted (i.e. there is no significant difference between observed and model-predicted values). The predictive success of the model was compared to the null model and the effect size was evaluated using Nagelkerke’s R^2 value.

Utilising the coding described above (Section 3.11), this was repeated for each of the three groupings: all patients attending the lung cancer clinic, newly diagnosed patients and patients who died within three months of LCQ completion.

3.11.7 Evaluation of Predictors of Increased Dyspnoea

One main question regarding dyspnoea is asked within POS: Over the past 4 weeks, have you been affected by shortness of breath?

- Not at all, no effect
- Slightly – but not bothered to be rid of it
- Moderately – breathlessness limits some activity
- Severely – activities or concentration markedly affected
- Overwhelmingly – unable to think of anything else’

The question can be answered from 0-4 (‘0’ being no dyspnoea and ‘4’ being overwhelmed by dyspnoea).

LCQ responses and other factors were compared between patients who felt lower dyspnoea (0-1) and those who felt higher dyspnoea (2-4). (Pearson chi squared testing was used for categorical data if larger than 2x2 tables and two-tailed Fisher's exact test was used for 2x2 tables). Statistically significant factors ($p<0.05$), those of clinical relevance and those identified in previous studies as of potential importance were then analysed by multivariate backwards logistic regression. Factors were included if $p<0.05$ and removed if $p\geq0.05$. Only statistically significant factors were included in the final model. This final model was assessed for goodness of fit utilising Hosmer-Lemeshow testing; non-significant values indicate the model is a good fit and the null hypothesis is accepted (i.e. there is no significant difference between observed and model-predicted values). The predictive success of the model was compared to the null model and the effect size was evaluated using Nagelkerke's R^2 value.

Utilising the coding described above (Section 3.11), this was repeated for each of the three groupings: all patients attending the lung cancer clinic, newly diagnosed patients and patients who died within three months of LCQ completion.

4 A Literature Review of Follow-Up of Patients with Lung Cancer

4.1 Methods

Computer searches were performed using MEDLINE, British Nursing Index (BNI) and EMBASE (Ovid SP, Ovid Technologies Inc., New York, NY), CINAHL (EBSCO Industries Inc., Birmingham, AL) and Cochrane Review. The search was limited from 1981 to 2009, articles published in English and referring to adults with lung cancer. The keywords used were: 'lung cancer follow-up' or 'lung cancer follow up, 'lung cancer care' and 'lung cancer surveillance'. From these articles, further references were identified and searched for manually. Included were articles and guidelines with specific reference to follow-up of lung cancer patients or lung cancer care within the title. All studies were reviewed and consensus guidelines included. All other articles were excluded.

4.2 Results

Eleven articles were found utilising CINAHL and a further 12 articles using MEDLINE, BNI and EMBASE and three from article references. No additional articles were identified from Cochrane Reviews. Within the identified articles and from additional hand searches, 26 articles were found in total. These have been tabulated and considered under three headings: (1) guidelines and reviews, (2) follow-up after curative intent and anti-cancer treatments and (3) different models of lung cancer care to conventional follow-up and patients' preferences.

Guidelines or reviews regarding follow-up in lung cancer			
Organisation/ Investigators	**Date**	**Population within guidance remit**	**Selected Guidance and statements**
ESMO[32]	2008	NSCLC	Optimal approach to follow-up noted to be controversial. For those with potential curative 'retreatment': • Follow-up 3-6 monthly for 2 years then 6-12 months thereafter. • Radiological investigation can be considered at these reviews.
ESMO[64]	2008	SCLC	Radiological follow-up of asymptomatic patients not clearly defined in literature. Follow-up should be considered. For patients who achieve long term survival, monitoring for a second primary should be considered.
ACCP[250]	2007	Follow-up of lung cancer patients after curative intent treatment	• Initial follow-up (3-6 months) by treating specialist to monitor for complications of treatment. • MDT decision to provide follow-up beyond initial phase for surveillance. • All patients should be counselled on symptom recognition. • Routine follow-up with CXR for CT 6 monthly for 2 years then annually. • Blood tests, PET, fluorescence bronchoscopy not routinely recommended.
SIGN 80[10]	2005	Patients with lung cancer	Paucity of research noted. Follow-up by clinical nurse specialists should complement conventional arrangements. Hospital follow-up recommended to continue if: • Reasonable prospect of hospital treatment or specialist advice being needed. • Where it is perceived to sustain a patient's morale. • After surgery, initial follow-up by the surgeon. • After chemotherapy or radical radiotherapy initial follow-up by treating specialist. After palliative radiotherapy either oncologist or respiratory physician Follow-up arrangements should be communicated to GP.
NICE C024[67]	2005	Patients with lung cancer	When patients finish treatment they should have a personal follow-up plan discussed and communicated to their GP. If Curative intent: • Member of MDT should routinely follow-up for 9 months with thoracic imaging as part of review. • Routine follow-up should not continue beyond 5 years. After chemotherapy or radiotherapy:

(continued)			• Review should occur one month after treatment cessation and CXR if indicated. After treatments patients with life expectancy of >3 months should have open access to a protocol-based nurse specialist service.
ACR[251]	2005	NSCLC	Follow-up with examination every 2-4 months for 2 years, 6 biannually to 5 years and annually for life. If curative intent: • CXR every 2-4 months (2 years), 6 monthly (to 5 years) then annually. • Routine CT at 3 months and then yearly. Different levels of CT surveillance are suggested for different initial stages and treatment combinations. It is noted that frequency of CT surveillance remains controversial in asymptomatic patients.
ASCO[252]	2003	NSCLC	If curative intent treatment: • Follow-up 3monthly with examination for 2 years then 6 monthly to 5 years, then annually thereafter. • Routine CXR not recommended, consider annual CXR if further curative intent treatment possible. • Routine CT or other radiological and blood tests not recommended. • Symptoms should drive appropriate investigations.
BTS[69]	1998	Lung cancer	Explicit, locally appropriate policies for follow-up should be agreed. Hospital follow-up recommended to continue if: • Reasonable prospect of hospital treatment or specialist advice being needed. • Where it is perceived to sustain a patient's morale. • After surgery, initial follow-up the surgeon. • After chemotherapy or radical radiotherapy initial follow-up by treating specialist. • After palliative radiotherapy either oncologist or respiratory physician.
Saunders et al[253]	2003	Consensus statement for follow-up of treated lung cancer	Lack of evidence base in follow-up. Initial follow-up should be by treating specialist and thereafter by member of MDT In curative intent: • 3 monthly review for 2 years then 6 monthly to 5 years. • Rapid interval access should be available to all patients. • CXR at each review. • No routine use of CT recommended.

(continued)			In Palliative Intent: • Initial follow-up dependent of anticipated treatment toxicity. • Thereafter frequency dependent on adequacy of symptom control, usually 1-2 monthly for 1st 6 months. • CXR at each review, routine CT not recommended.
Colice et al[254]	2003	Follow-up of lung cancer patients after curative intent treatment	• Treatment complications should be managed by treating specialist in first 3-6 months. • Thereafter follow-up by member of MDT. • Initially review and radiographic investigation 6 monthly for 2 years and then annually. • Patients should be counselled on symptom recognition. • MDT should oversee surveillance programme. • Other investigations not routinely recommended.
Alberts[255]	2007	Follow-up after surgery	• Lack of evidence base. • Increased frequency in first 2 years then reduced. • Life-long surveillance recommended in most guidelines reviewed. • Symptom recognition and monitoring is key to follow-up. • Use of CXR and CT more controversial. • MDT, GP or nurse-led follow-up models all advocated within literature.

Table 7: Guidelines or reviews regarding follow-up in lung cancer.

Lung cancer follow-up after curative intent and active anti-cancer treatments					
Investigators	**Design**	**Sample**	**Histology**	**Selected Findings**	**Conclusions**
Gilbert et al[256]	Retrospective Longitudinal	245 post-resection patients with early stage disease (≤II)	NSCLC	45.3% of patients had recurrence. Despite clinic follow-up, 70.3% of detected recurrences were identified by family doctor. 67.5% of recurrences had associated symptom or clinical changes. Of the asymptomatic recurrences, 78.2% had an abnormal CXR. 24.2% were identified by CXR alone and 69.7% using multiple modalities. Symptoms at time of recurrence associated with reduced survival. No significant difference in survival between recurrences detected by family doctor or through clinic (For asymptomatic and symptomatic groups). 64.9% of recurrences were extra-thoracic. Only 2.3% of recurrences detected by examination alone.	Most recurrence is extra thoracic. Despite routine review more recurrence detected by family doctor than clinics. Most recurrences associated with symptoms. 93.7% overall identified by history, examination ±CXR. Could nurse-led or telephone review identify recurrences?
Walsh et al[257]	Retrospective Longitudinal	358 patients after complete resection of lung cancer	NSCLC	Overall 5 year survival 54%. 37.7% had recurrence, 67% of which were extra-thoracic. Recurrence by initial pathological stage: I – 24.2%. II – 48.9%. 3a and 3b – 54.5%. 24 % of recurrences were asymptomatic, 79% of which had abnormal CXRs. Physical examination alone detected recurrence in only 2 patients. Of the 102 symptomatic recurrences only 29% were retreated with curative intent. Of the 33 patients with asymptomatic recurrence only 10(30%) were retreated with curative intent. 3 of the 10 died within study period. Symptoms at recurrence predicted lower survival. 9.8% of patients developed other malignancies during study. (50% within aerodigestive tract). Around 50% of patients who developed symptoms returned for assessment before a scheduled clinic.	Routine follow-up by physician altered treatment strategy in <3% of patients. Routine follow-up (6 monthly) with CXR recommended for first year postoperatively then yearly CXR's and symptom driven review.

Younes et al[96]	Retrospective Longitudinal	130 patients after complete resection of lung cancer 2 Groups: 67 patients routine follow-up 63 patients symptom driven follow-up Groups occurred due to follow-up policy change	NSCLC	No difference in disease free survival between the two groups (p=0.219). Local recurrence detected in 1.4% of strict follow-up compared to 3.1% in symptom group. Significantly higher rate of consultations in strict routine group (5.9 visits/year compared to 3.25 visits/year). Twice as many CXR's performed in routine group and 6 times as many CT scans. Cost of follow-up was higher in routine group. Routine follow-up did help detect other health issues and there were less emergency attendances and hospital in-patient days in this group. 91.4% of patients with recurrence died within 2 years.	Routine follow-up did identify other health problems beyond lung cancer. These costs were mainly due to investigations and consultation cost. Routine imaging was not shown to be of absolute benefit but authors recommend use of CXR 6 monthly. As early detection of pre-symptomatic recurrence does not translate into improved survival, intense follow-up not recommended.
Virgo *et a*[258]	Retrospective Longitudinal	182 early stage (<3A) resected lung cancer. 62 non-intensively followed and 120 intensive Groups defined retrospectively through service use	NSCLC	Significant variance in follow-up strategies within this single centre study. Test and visit frequency did not influence outcome. Time to detection of recurrence did not differ. Survival did not differ significantly between the two groups.	Wide variation in follow-up practice. No difference between intensive follow-up and non-intensive for patient outcomes. QOL not evaluated.

Westeel *et a*[259]	Prospective Longitudinal	192 post surgical lung cancer patients	NSCLC	Study to test feasibility of intensive follow-up with review and CXR 3 monthly, bronchoscopy and CT scan 6 monthly. Recurrence detected by scheduled procedure in 63% and non-scheduled symptom driven procedures in 37%. In recurrences detected by scheduled procedures 35 (26%) were asymptomatic. 10 detected by CT and 10 by bronchoscopy. Extra-thoracic recurrence in 48%. Curative intent treatment undertaken by 10 (5% overall) asymptomatic patients. 7 of these patients survived to 3 years from recurrence. Symptomatic recurrence was associated with reduced survival. 11% developed secondary new malignancies, mostly aerodigestive tract. Intense follow-up was more expensive and estimated around 13,000 dollars per year of life gained.	Intensive follow-up is feasible and accepted by patients. Asymptomatic patients at recurrence had a slightly longer survival than symptomatic patients. Increased risk of second malignancies. 80% of asymptomatic recurrences were intra-thoracic. Intensive follow-up may be cost-efficient in terms of life years gained.
Lamont et al[260]	Retrospective Longitudinal	124 patients with stage resected lung cancer	NSCLC	CT follow up of lung nodules identified within first year post-operatively. Probability of developing a second primary lung cancer (SPLC) was 2.1% per patient per year. All SPLC detected were asymptomatic. Of the 19 (15%) patients with SPLC, 18 (14.5% overall) were potentially resectable Only 14 underwent resection and 9 (7.2% overall) had no evidence of disease at 20 months. Median disease free survival for SPLC was 35 months and 28 months for local recurrence.	Staging of second primary lung cancer is poorly defined. Those with SPLC at stage 1A have improved survival compared to those with more advanced disease receiving similar treatment. Local recurrence has a poor prognosis. Annual CT surveillance may improve detection of asymptomatic or pre-symptomatic lesions.

Benamore et al [261]	Retrospective Longitudinal	75 patients with advanced post treatment lung cancer (IIb to IIIb) 40 patients in trials and 35 non-trial patients (Less frequent follow-up and no routine CT)	NSCLC	60% recurrence or new primary. 64% of recurrences detected after patient sought review between scheduled appointments (equal numbers between groups). In the 44 patients with confirmed relapse biochemistry was normal in 88.6%. No patients had altered bloods as sole presenting feature of relapse. No difference in time to relapse between groups. No overall difference in survival between groups. Symptomatic recurrence associated with reduced survival. Isolated thoracic recurrence only detected in 6 (14%). 2 underwent curative intent retreatment, 1 survived >4 months.	Detection of recurrence or new primary should only be sought if treatment possible. No difference in overall survival between groups found. Most recurrences had extra-thoracic disease evident. Routine blood tests did not contribute to survival outcomes. Routine CT did not contribute to survival outcomes.
Perez et al[262]	Retrospective Longitudinal	115 patients with complete response to initial treatment but subsequent progression 58 patients with limited disease 57 extensive stage	SCLC	49% recurrences occurred within one year. 44% in the second year. Time to progression longer in limited stage. Recurrence signalled by history in 71% and examination in further 10%. Symptoms of recurrence were not subtle. In asymptomatic recurrences were detected by CXR (12%), blood tests (6%) and CT (1%). 59% of recurrences were detected between scheduled appointments. Symptomatic recurrence was associated with reduced survival. At recurrence, 33% were given supportive care, 41% chemotherapy, 20% radiotherapy and 5% combined modalities. All 115 patients died within follow-up period. Median survival 115 days (range 1-793 days).	Follow-up in SCLC does not allow identification of potentially curable patients. RCT's are not needed for follow-up strategies but utilise retrospective data to develop appropriate, cost effective follow-up.

Sugiyama et al[263]	Prospective Longitudinal	94 SCLC patients who had shown partial or complete response to first line chemotherapy Grouped into intense (n=62) or non-intense (n=32) follow-up	SCLC	Intense included routine CT of chest and upper abdomen/CT or MRI brain and bone scan every 2 months (for 6 months) then quarterly for 1.5 years. Non-intense investigations by request. Disease recurred in 88.7% in intense group and 90.6% of non-intense. Asymptomatic recurrence in 65.5% (intense) and 41.4%% (non-intense) (p=0.03). No difference in groups in time to recurrence. Salvage chemotherapy delivered more often in intense group. Overall survival greater in intense group (Median survival of 20 months compared to 13 months).	Intense follow-up may identify recurrence within asymptomatic patients and allow salvage chemotherapy before decline in PS. Survival was longer in intense follow-up group. 20% of recurrences were detected with brain scanning. >90% of recurrences occur within 2 years. Cost effectiveness not assessed. 34% of recurrences in intense group were detected due to signal symptoms.

Table 8: Lung cancer follow-up after curative intent and active anti-cancer treatments.

Different models of care for lung cancer follow-up and patients' preferences					
Investigators	**Design**	**Sample**	**Histology**	**Selected Findings**	**Conclusion**
Moore et al[264]	RCT	203 lung cancer patients who had completed initial treatment and life expectancy >3 months	Mixed NSCLC, SCLC and Mesothelioma Randomised to nurse-led follow up (100) or conventional follow-up (103)	Nurse-led follow up was acceptable to patients (75%). Reduced dyspnoea, better emotional functioning and less peripheral neuropathy in nurse-led group. No differences seen in overall survival or rates of progression. Nurses recorded progression of symptoms sooner than doctors. Patients in nurse-led group were more likely to die at home, had fewer CXRs and had more palliative radiotherapy. No cost differences found. No other differences found between groups.	Follow-up by nurse specialists is safe, acceptable and cost equivalent. No patients in nurse-led group wanted to revert to conventional treatment at end of study. 43% of patients in nurse-led group died at home compared to 23% in medical follow up. No differences in survival seen and symptoms detected sooner.
Williamson *et a*[265]	Audit Cross sectional	40 lung cancer patients attending a new nurse-led clinic (100% response)	Not stated	Initially 57% would have preferred to see a doctor. 100% were satisfied with information given. Future review 30% wanted nurse-led, 40% had no preference and 30% alternate doctor and nurse. 100% were satisfied with nurse review.	Satisfaction with nurse-led clinic was high. However majority of patients would have preferred medical review.
Adlard et al[223]	Service Description	160 patients from lung MDT post palliative intent treatment	Majority NSCLC but also SCLC, clinical and Mesothelioma	No routine appointments made, open access if requested by patient or professional. 43 % had one open access visit, 15% 2 visits, 9% 3 visits and 33% did not visit. 90% of visits related to symptoms. All visits were considered appropriate by MDT. 50% of patients seen within 4 days of request. Most clinic visits arranged through macmillan	Fewer clinic visits overall compared to predicted routine schedules. Access was rapid. Macmillan nurses had pivotal role. Symptoms were main reason to return. Some patients would have preferred routine return (22%).

(continued)				nurses. 22% of patients would have preferred routine review.s	Increased telephone contact out of hours. 21 patients did not use service at all.
Temel et al[266]	Prospective Longitudinal Feasibility Phase 2 trial	51 Newly Diagnosed ambulatory advanced lung cancer patients	NSCLC (IIIb or IV)	Feasibility study of integrating palliative care into follow-up and supportive care of newly diagnosed advanced lung cancer patients 90% complied with at least 50% palliative care visits. Number of visits ranged from 0-17 (median 6) All participants surviving >6months chose to continue to meet with palliative care after study completion. High symptom burden confirmed through QOL and symptom questionnaire.	Early palliative care input was feasible. Patients surviving >6months chose to continue with palliative care input. Symptom burden was high. Palliative care could be integrated into follow-up of advanced NSCLC patients from diagnosis.
Pitorak et al[144]	Service Description	Advanced (IIIb and IV) lung cancer	NSCLC	Outline of 'Project Safe Conduct', integration of palliative care into comprehensive cancer care Joint working and cross education between palliative care team and oncologists. Presence in clinics for breaking of bad news and symptom control. Patient focused care with appropriate interventions discussion individually within disease trajectories. Extended care for the family. Secondary care integrated with community visits. Culture change.	Successful integration of palliative care service with oncology lung cancer care. Cross specialty training and joint clinics. Bridge between secondary and primary care. Bridge across transitions of care – active treatment to symptom control to end of life.
Cox et al[267] *(continued)*	Cross sectional	34 lung cancer patients, post treatment eligible to attend a nurse-	NSCLC or SCLC	20% of MDT patients considered suitable for nurse-led follow-up. Main symptoms were fatigue, dyspnoea and pain.	Doctor follow-up more acceptable to patients and relatives. Nurse-led follow-up may be more acceptable if rapid access to doctor

	led clinic	Mean global QOL was at mid point on EORTC QLC C30 score. Majority had seen a doctor in MDT clinic. Majority wanted a check up and reassurance, less had specific problems they wanted to raise Reassurance was rated as the most useful component of review. 67% felt no component of the review was 'not useful'. Patients were significantly happier with future medical follow-up compared to nurse-led or telephone follow-up. Nurse-led follow-up was more acceptable than GP follow-up.	also available. Symptom burden high in NSCLC. 20% patients considered suitable for nurse-led follow-up at outset.

Table 9: Different models of care for lung cancer follow-up and patients' preferences.

Most of the NSCLC studies regarding follow-up after curative intent treatments were retrospective, longitudinal studies (n=5)[256-258, 260, 261] comparing intensive with less intensive follow-up, trial-based follow-up against standard care or observational studies of the effect of intensive follow-up. Retrospective grouping was possible due to changes in protocols, participation in trials and data on service usage. One study was prospective in design.[259] There were only two studies looking at follow-up methods in SCLC, one retrospective and one prospective.[262, 263] The only randomised controlled trial (RCT) evaluated nurse-led follow-up against conventional medical follow-up in stable patients who had completed palliative treatments.[264] Other than this RCT, the other studies relating to alternative models of follow-up or patient preference were: feasibility studies, audit, a prospective survey, qualitative or service descriptions.

Intensive follow-up was variably defined within the studies. Definitions included: patients within trial protocols (compared to routine review),[261, 262] standard care (compared to open appointments), frequent scheduled review with chest x-ray ((CXR) compared to less than three scheduled reviews per year but open return),[96] routine review and CXR three monthly with CT scan and fibreoptic bronchoscopy six monthly,[259] four or more appointments per year or four or more multichannel blood tests per year or four or more CXR per year or bronchoscopy or sputum screen (compared to none of above),[258] and three monthly CT surveillance of any nodules detected on post-operative scan.[260] The most intensive follow-up protocol included regular review, blood tests, CXR, two monthly CT of thorax, abdomen and brain and bone scan for six months then quarterly for one and a half years. This was within a prospective study of SCLC patients with complete or partial response to first line chemotherapy.[263] Four studies contain information regarding symptom status at time of recurrence after curative intent surgery (Table 10).

	Gilbert et al[256]	Walsh et al[257]	Younes et al[96]	Westeel et al[259]	Total
Sample Size	245	358	130	192	925
Recurrence	111 (45.3%)	135 (37.7%	33 (25.3%)	136 (70.8%)	459 (49.6%)
Symptomatic Recurrence	55 (22.4%)	102 (28.5%)	16 (12.3%)	100 (52.1%)	303 (32.7%)
Asymptomatic Recurrence	31 (12.7%)	33 (9.3%)	17 (13.1%)	36 (18.8%)	131 (14.1%)
Detected by Physical Exam Alone	2 (0.8%)	2 (0.6%)	3 (2.3%)	Not reported	7/733 (0.9%)
Asymptomatic and Detected by CXR	8 (3.3%)	26 (7.3%)	5 (3.8%)	12 (6.3%)	56 (6%)
Asymptomatic & detected by CT	0 (0%)	4 (1.1%)	7 (5.4%)	13 (6.8%)	33 (3.6%)
Asymptomatic & detected by Bronchoscopy	0 (0%)	0 (0%)	Not reported	10 (5.2%)	10/795 (1.3%)
Detected at scheduled appointment	26 (10.6%)	Not reported	Not reported	85 (44.2%)	111/437 (25.4%)
Symptoms at recurrence adverse prognostic factor	Yes	Yes	Yes	Yes	Yes

Table 10: Summary of number, mode and symptom status of recurrence detection in patients who have undergone curative intent surgery for NSCLC. Percentages of total number of patients in each study in brackets.

4.3 Discussion

Lung cancer follow-up has a very low evidence base. Studies have tended to focus on follow-up strategies in patients with NSCLC who have undergone curative intent surgical resection. The main focus has been on trying to establish optimal frequency and intensity of investigations in follow-up. There have been fewer studies into follow-up after treatment for SCLC and even less into follow-up after palliative treatments or during supportive care provision. The important outcomes have generally been considered to include: overall survival, disease-free survival and cost-effectiveness. There has been little attempt to evaluate the best structures to address quality of life issues and to meet supportive care needs of patients within these studies. There have also been few studies addressing patient and carer satisfaction with follow-up structures.

4.3.1 Guidelines Relating to Follow-Up

Within Europe, guidelines that describe appropriate follow-up include Scottish Intercollegiate Guideline Network (SIGN) guideline 80,[10] National Institute for Health and Clinical Excellence (NICE) guideline 24,[67] European Society for Medical Oncology (ESMO)[32, 64] and the British Thoracic Society (BTS) guidelines.[69] Another recent guideline regarding lung cancer management has been issued from the American College of Chest Physicians (ACCP).[250] Further American guidelines are available from

the American Society of Clinical Oncology (ASCO)[252] and the American College of Radiology.[251] There are dramatically conflicting views regarding follow-up structures and methods, and this is recognised in many of these guidelines. ESMO note that 'the optimal approach to post-treatment management of patients with thoracic malignancies, including the role of radiological evaluation, is controversial.'[32] SIGN guideline 80 comments that in regard to follow-up of lung cancer patients 'there is a paucity of good quality research in this area'.[79] As such, the recommendations remain flexible and open to local interpretation, although the local policy is also expected to be *explicit* and *clear*.[69] The majority of guidance is related to follow-up of post-curative intent treatments in NSCLC, although ESMO gives specific guidance related to SCLC[64] and the UK guidelines are general for all histology subtypes. The ACCP has also issued guidance related to the palliative care of lung cancer patients. Guidance from the USA is more likely to suggest defined frequencies of follow-up and utilisation of radiological investigations. The European and British guidance is more general and allows for local flexibility.

All the guidelines tend to suggest initial follow-up should be carried out by the treating specialist, either thoracic surgeon post-operatively or oncologist after radical radiotherapy or chemotherapy. However, the BTS guidelines state that 'it should be clear to patients who their supervising consultant is.'[69] Once the initial phase is complete (ranging from three to twelve months), the patient's needs and goals should be reviewed by the MDT and structured follow-up arranged to meet those needs. After palliative treatments, the guidance is less clear as to who should lead follow-up and may leave this to local agreement. In the curative intent setting, the majority of American guidelines advocate frequent initial follow-up (two to four monthly), reducing to bi-annually at two years and then annually at five years. European and UK guidelines also recommend more frequent follow-up in the first two years. In the USA, follow-up is generally recommended to be life-long. In contrast to this, NICE guidelines state follow-up should cease at five years.[67] The reviews and consensus statements tabulated above outlined similar strategies for duration of follow-up.[253-255]

Regarding alternative models of care, SIGN and NICE guidance recognise the role of a nurse specialist and recommend access should be available to such a service for all patients in follow-up with life expectancy of greater than three months. They acknowledge the only randomised controlled evidence for follow-up supports the case

of nurse-led care in selected patients. Many of the guidelines emphasise the importance of symptoms within lung cancer care. They advocate counselling to make patients aware of this and which symptoms to be alert to. ASCO guidance recommends a symptom-driven approach to use of radiological investigations.

Each of the guidelines promotes the role of multidisciplinary team working and good communication. BTS, SIGN and NICE guidance all state that communication regarding follow-up with the patient, and also with the primary care physician with responsibility for community care of that patient, is vital.

4.3.2 Follow-Up After Curative Intent Treatments

When curative intent treatment has been provided, the follow-up is firstly structured to assess response and attend to treatment complications. Current guidelines suggest the treating specialist should provide follow-up for this purpose for a period of at least three to six months.[250] Secondly, follow-up provides surveillance for recurrence or second primary lung cancer (SPLC). There is no solid evidence available to guide best practice; however, for patients with the potential for curative *re-treatment*, current guidance suggests a history and physical examination should be performed every three to six months for the first two years and every six to twelve months thereafter. Radiological examinations are to be considered at these intervals within ESMO guidance[32, 64] but are suggested every six months within the ACCP guidance.[96, 250, 253, 254, 257]

Detection of SPLC in post-operative patients with NSCLC was specifically addressed by Lamont et al.[260] Evaluating follow-up with intensive post-operative CT scan surveillance, this retrospective study analysed 102 patients who had pulmonary nodules identified on a post-operative scan. Nineteen of these patients were diagnosed with a SPLC (overall probability of developing a SPLC was 2.1% per patient per year) and 16 were staged as 1A. Only 11 of the 19 identified second primary lung cancers were identified by CT scanning. Fourteen patients with SPLC underwent further surgery and nine remained without identifiable disease for a median of 20 months (Range 4-56 months). The authors concluded there is a role for CT surveillance to detect early stage second primaries to allow curative intent surgery to be delivered.

It is recognised that co-morbidity and co-malignancy are common in patients with lung cancer. Walsh et al[257] reported that within their study of 385 patients with resected

NSCLC, 66 (17%) had one additional malignancy, either prior to study entry (42) or during follow-up. The identification of new non-lung cancer primary malignancies during studies have been reported in up to 11% of patients undergoing follow-up after curative intent surgery for NSCLC.[257-259] However, Virgo et al[258] found that identification of second primaries did not significantly differ (p=0.57) between the non-intense follow-up group (n=5/46, 10.9%) and the intense follow-up group (n=16/112, 14.3%).

Non-malignant health issues are also common in the lung cancer population.[190, 268] Janssen-Heijnen et al[268] report from a study of 3864 lung cancer patients a high prevalence for diseases related to smoking: cardiovascular disease (23%) and chronic obstructive pulmonary diseases (22%). In this study, they also found a co-malignancy prevalence of 15%.

Younes et al[96] found an additional purpose of frequent review was the identification of non-malignant health issues in a timely fashion. They reported that the patients frequently seen by a specialist had less emergency room attendances and less in-patient bed days, translating into a lower cost for care of non-lung cancer related issues. This cost benefit was not sustained when off-set by costs of intensive surveillance and radiological investigations.

At time of diagnosis of NSCLC, less than 20% are suitable for curative intent surgery.[55] From the studies detailed in Table 10, only 14.1% (9.3-18.8%) of the populations studied who did proceed to surgery had no symptoms at the time recurrence was detected; 6% (3.3-7.3%) had the recurrence detected by chest radiographs; 3.6% (0-6.8%) by CT scan of chest, abdomen or brain and less than 2% by bronchoscopy. In the two studies reporting detection of recurrence at a scheduled appointment (review or surveillance investigation), 25.4% (10.6-44.2%) of recurrences were detected at one of these appointments. Walsh et al[257] note that nearly half of the patients in whom symptoms developed returned at an unscheduled time for review. It is of note that in each study the presence of symptoms at diagnosis was an adverse prognostic factor; this was often true when comparing median survival from diagnosis, operation or recurrence.

A fourth purpose to follow-up could be to provide a platform for assessment of ongoing symptoms or supportive care needs related to either the disease or the treatments provided.[139] This and quality of life issues were not addressed in any of these studies evaluating follow-up methods. In the curative intent setting, supportive care needs and symptoms have not traditionally been given high importance. Sarna et al[269] have reported high prevalence of symptom and psychosocial distress within 94 patients one, two and four months post-thoracotomy. Prevalence of the severe symptoms included: fatigue (57%), dyspnoea (49%), cough (29%) and pain (20%). Mean symptom distress reduced over time for most symptoms, but only anorexia, pain and dyspnoea had significantly improved by four months. It was also noted that 77% of patients in this group had a co-morbid condition. It may be that integration of symptom-focused care into follow-up would add additional purpose. In addition to this, the systematic assessment of symptoms may also identify patients with changing symptoms sooner than conventional follow-up. It may be that some of the patients described as 'asymptomatic' from retrospective case note review had unidentified or low level, but changing, symptoms present. It is of note that in the study of Moore et al[264] of nurse-led follow-up, median time to detected symptom progression was significantly (p=0.01) lower in the nurse-led clinic (six months) compared to conventional medical follow-up (10.2 months), despite objective progression rates being the same (8.3 months in nurse-led follow-up compared to 10.2 months, p=0.47). The nurse-led clinic utilised the European Organisation for Research and Treatment of Cancer Quality of Life Score (EORTC QLQ-C30) with lung cancer module 13 (LC13) to systematically assess quality of life and symptoms. In the above studies, the small percentage of detected 'asymptomatic recurrence' may also have included a percentage of undetected symptoms.

4.3.3 Follow-Up in Small Cell Lung Cancer

Only two studies were identified that looked specifically at follow-up in SCLC. The first paper considered those who had achieved a complete response following first line chemotherapy within the context of three clinical trials.[262] Of the 115 patients considered (58 with limited disease and 57 with extensive disease), recurrences occurred in 49% in the first year, 44% in the second year and 7% after two years. Within the follow-up period, 100% of patients died, with the median survival after recurrence being 115 days (range 1-793 days). It was noted that 59% of recurrences were identified between scheduled visits due to symptom development. The authors

noted that the symptoms occurring were not trivial or subtle but made it evident that disease status had changed. In all, recurrences were detected by history in 71% of cases and by additional examination in a further 10%. Of the 19% not detected by clinical history or examination, a further 12% were diagnosed through CXR abnormalities, 6% by altered biochemistry and only 1% by CT scan. Signalling of disease progression by clinical factors was significantly more common in those with extensive disease. The authors concluded that clinical history and examination was the mainstay for recurrence or progression in SCLC. CXR added some additional value but blood tests were of little benefit.

In contrast, Sugiyama et al[263] suggested that intensive clinical and radiological follow-up did improve detection of recurrent or progressive disease and translates into improved survival. They evaluated 94 patients with complete or partial response to first line chemotherapy for SCLC. Fifty-five patients underwent very intensive follow-up, consisting of frequent review and CXR, two monthly non-enhanced CT (of chest, upper abdomen and brain) and bone scan for the first six months and then quarterly for a further 18 months. For the remaining 39 patients (non-intensive follow-up), investigations were at the discretion of the clinician. All patients received regular review (monthly for two years, then bimonthly for an additional three years). Patient characteristics and treatment received was similar in both groups. The authors also noted that no patient in either arm received prophylactic cranial radiation. On identification of recurrence or progression, either salvage chemotherapy was delivered (within limits of PS $\leq$ 3) or whole-brain irradiation for brain disease. Those with PS of 4 were provided supportive care. Eighty-four (89%) patients had a recurrence detected overall with no significant differences in sites of recurrence between the two groups. Forty-two percent of recurrences were symptomatic; 58% asymptomatic. Fourteen percent of recurrences were detected on CXR (25% of asymptomatic recurrence), 34.5% through CT of chest or abdomen, 15.4% brain scan and 4.7% through bone scan. At time of detection of recurrence, the number of patients with PS of 4 was less in the intensive follow-up group than the non-intensive group (9.1% compared to 27.6%, p=0.03). In keeping with this, more patients in the intensive group received salvage treatment. Overall median survival was longer in the intensive group (20 months, 95% CI 14-27 months) compared to the non-intensive group (13 months, 95% CI 9-15 months, p=0.04). The authors do not address cost-effectiveness or quality of life issues.

4.3.4 Follow-Up in Non-Curative Non-Small Cell Lung Cancer

After palliative treatment, follow-up assesses response, monitors and responds to side effects and provides supportive treatment.[55, 253] There is no clear guidance as to the best frequency or structure for this follow-up. There is also no clear evidence as to who is best placed to provide follow-up and who patients wish to provide such follow-up. Hospital-based follow-up is currently recommended to continue where there is 'a reasonable prospect of hospital treatment or specialist advice being needed, … where this is perceived to be important to sustain a patient's morale,' and after treatments given to monitor response and side effects.[69] NICE guideline 24 recommends that a personal follow-up plan should be agreed and patients' views obtained for service development.[67] SIGN guideline 80 impresses the need for 'a patient centred approach [and] effective communication throughout the cancer journey.'[10]

Benamore et al[261] addressed the use of intensive follow-up in patients with stage 3 NSCLC receiving palliative treatments. They compared 40 patients within trial protocols and 35 patients who had received standard treatments. Patients within the trial protocol had significantly more CT scans of thorax, abdomen and brain but had the same frequency of review. They concluded that despite the trial group having a higher number of asymptomatic recurrences diagnosed, there was no overall benefit in survival.

Three studies addressed the use of nurse-led follow-up in selected lung cancer patients who had completed initial treatment.[265, 267, 270] Moore et al[270] found acceptability of nurse-led clinics to be 75% and noted earlier symptom progression detection without any significant differences in objective progression or overall survival. Of note, patients undergoing review by the nurse were much more likely to die at home, had fewer chest x-rays and were treated with more palliative radiotherapy than those within conventional follow-up. An audit by Williamson et al[265] found high levels of satisfaction with the service provided by the nurse-led clinic but the majority would have preferred to see a doctor instead (57%). This finding was in keeping with Cox et al.[267]

Two publications addressed the integration of supportive and palliative care services within lung cancer clinics. Temel et al[266] demonstrated the feasibility of such integration and Pitorak et al[144] described a service in operation. Both papers suggested early

integration is acceptable to patients, and the benefits of cross-education, bridging illness journey transitions and symptom control were noted. Adlard et al[223] described another model of care based on rapid return to open access appointments. No routine appointments were made for patients who had completed palliative intent treatments. The authors described 90% of return visits related to symptoms and the majority were arranged through the community palliative care nurse. Only 43% of patients requested review and most were seen within a week. The authors noted that, from the responders to a questionnaire, 22% of patients would have preferred a routine review.

4.3.5 Patients' Views Regarding Follow-Up

Traditional follow-up has usually been provided on a routine basis with fixed appointments for on-going review. These reviews are carried out by medical staff and often are accompanied by routine imaging or blood tests. Alternative models of care include:

- hospital based, specialist nurse-led clinics;
- open access clinics with patient-led, symptom driven assessment;
- discharge to community with community services follow-up;
- discharge to care of palliative services.

There is some evidence that specialist nurse-led clinics can be as effective as medical-based follow-up in terms of clinical care and cost efficiency.[264, 270, 271] However, it may be that patients would prefer routine medical follow-up compared to nurse-led follow-up or general practitioner (GP) follow-up.[267] Additionally, very little is known about the effects of routine follow-up and what value patients place upon it.[267, 272] It has been reported that patients with advanced lung cancer can feel apprehensive about out-patient appointments but do wish on-going review and prefer review chest x-rays despite knowing their cancer is incurable.[273] It has also been reported that patients can feel a sense of abandonment when discharged from the hospital-based service which has undertaken investigation and initial treatments. This is associated with increased psycho-spiritual distress (see Figure 6).[180]

4.3.6 The Role of Symptoms in Follow-Up

Even in the context of curative intent treatment there is little evidence to support routine follow-up or routine imaging compared to symptom driven follow-up.[96, 254, 257, 274] In

most of the guidelines which address follow-up within lung cancer, symptoms are pivotal to recognition of recurrence or progression. It has also been noted that, given the poor prognosis and high symptom burden in lung cancer, symptom control and quality of life management should be integrated into lung cancer care.[139, 250, 275] Symptoms may also give additional prognostic information at the time of recurrence, alongside disease-free survival time and performance status. Such prognostic information could be used to trigger appropriately paced referrals for symptom control or palliative oncological interventions. It has been suggested symptom driven follow-up may be appropriate for the patients in whom goals are symptom control and improved quality of life (this may include those with incurable disease at diagnosis, those who are unfit for curative treatment and those in whom curative treatment has been provided but would be unfit for second line treatments). It is important to utilise systematic symptom assessment in the cancer setting, as many distressing symptoms may not be spontaneously reported by patients.[276] Furthermore, it should be recognised that the distress associated with any given symptom may not be determined solely by its severity.[224]

4.4 Conclusions

There are 37 million follow-up appointments within the National Health Service (NHS) each year. Of all outpatient 'Did Not Attends,' 75% are for follow-up appointments.[277] Follow-up for cancer patients has been identified for particular attention to 'ensure that follow-up procedures for cancer patients are clinically appropriate, make the best use of resources and enhance the experience for patients.'[277] Appropriate follow-up will differ for individual situations. Follow-up arrangements should consider patients' wishes and goals, stage of disease, treatment delivered, local resources, survival outcome and supportive care needs. In lung cancer, there are three main follow-up pathways: after curative intent treatment, after palliative intent anti-cancer treatment and those for who best supportive care alone is being provided. These different 'streams' of care may be underpinned by different strategies overviewed by the multidisciplinary team. One such model has been outlined by NHS cancer improvement services, based on the British Thoracic Society guidelines (Figure 7).[69, 277]

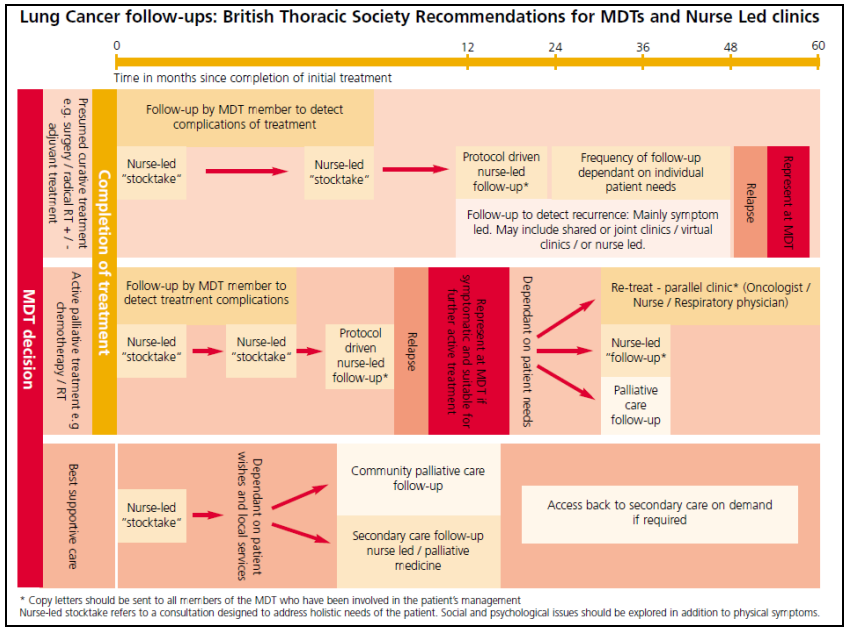


Figure 7: BTS guidelines for follow-up summarised.[277] Reproduced from *The How To Guide: Achieving Cancer Waiting Times* with the permission of the Cancer Services Collaborative Improvement Partnership, NHS.

It is clear that there are many health care professionals positioned to be able to provide follow-up for lung cancer patients, but it is not clear who, or which mix, produces the best provision at each stage of the illness trajectory. In those for whom curative intent treatment has been delivered, there remains debate whether intensive follow-up is efficient and effective and to what level radiological investigation should be integrated within such follow-up. In particular, it is not clear if asymptomatic (or pre-symptomatic) disease can be identified to produce improved survival without disrupting quality of life and within cost-effective limits. Furthermore, most of the studies within the literature are retrospective and defined 'asymptomatic' from case note entries rather than utilising systematic symptom assessment tools to identify any low level symptoms. It is possible that systematic symptom surveillance would reduce the low number of 'asymptomatic recurrences' detected within these studies.

In the majority of patients who received palliative intent treatments, a variety of models of care appear to be feasible but require further evaluation to determine the model which best meets patients' needs and delivers on outcomes. In those receiving supportive care, there may be an additional tension for patients who wish local, community-based care but continue to seek reassurance from hospital-based services.

An ‘enhanced experience’[277] for patients is likely to be gained from providing a holistic service. There is a challenge to structure follow-up to provide four dimensional care: physical, social, psychological and spiritual. Such a concept has been described for end of life care by Chochinov et al;[278-280] ‘dignity-preserving end of life care’ encourages consideration of symptom control, social support, and existential comfort as an integrated package. This, or similar approaches, may be integrated at earlier points within the lung cancer disease trajectory in the future.

5 A Literature Review of Symptoms in Lung Cancer

Cooley et al[1]published a systematic review of symptoms in adults with lung cancer in 2000, limiting their search to articles published between January 1982 and August 1998, identified using MEDLINE and Cumulative Index of Nursing and Allied Health Literature (CINAHL). Their review has been extended to include more recent articles and it referenced articles from before 1982 from a wider range of literature indices.

5.1 Methods

Computer searches were performed using MEDLINE, British Nursing Index (BNI) and EMBASE (Ovid SP, Ovid Technologies Inc., New York, NY), CINAHL (EBSCO Industries Inc., Birmingham, AL) and Cochrane Review. The search was time limited to between August 1998 and February 2009, articles published in English and referring to adults with lung cancer. The keywords utilised by Cooley et al[1] were repeated: 'symptoms and lung cancer' and 'symptom distress and lung cancer'. In addition, a further search term was added: 'symptom burden and lung cancer'. From these articles, further references were identified and searched manually.

Inclusion criteria were specific reference to symptoms of lung cancer within the title or clearly stated symptom prevalence results within the abstract. All other articles were excluded.

5.2 Results

Thirty-six articles were found utilising CINAHL and a further 356 articles using MEDLINE, BNI and EMBASE. No additional articles were identified from Cochrane Reviews. Within the identified articles and from additional hand searches, a total of 21 new articles were found. The previous review identified 18 articles in total over the period of January 1982 to August 1998, making a total of 39 articles identified over the period from 1982 to 2009. These have been tabulated and considered in reference to the stage of the lung cancer journey on which each study focused: initial presentation, new or recent diagnosis, diagnosis established and treatment or follow-up ongoing, patients receiving palliative or supportive care without active anti-cancer treatments and long term survivors. There is some overlap within these phases, but each article has been

positioned according to its main focus. A summary of design, sample type and size, symptom measures, symptom prevalence and main findings has been tabulated (Table 11 to Table 15).

Symptoms at presentation				
Investigators	**Design**	**Sample**	**Instruments Utilised**	**Selected Findings**
Hamilton et al[82]	Retrospective Case-control	247 lung cancer patients at initial presentation to primary care Compared to 1235 age, sex and practice matched controls	Case note review	Most common symptoms: cough (65%) dyspnoea (56%), chest pain (42%), fatigue (35%) weight loss (27%), haemoptysis (20%) & anorexia (19%). Many of these symptoms prevalent in control population. Haemoptysis as presenting single symptom had greatest Positive predictive power (2.4%). Combination of symptoms increased PPP *e.g.* Haemoptysis and anorexia PPV >10%. Dyspnoea was usually accompanied by another symptom which helped target investigation (dyspnoea in controls 16%).
Beckles et al[66]	Review of initial evaluation of presenting patients	Prevalence of presenting symptoms tabulated from 8 pre-1997 studies	Various	Range of presenting frequencies of symptoms: Cough (80-75%), weight loss (0-68%), dyspnoea (3-60%), chest pain (20-49%), haemoptysis (6-35%), bone pain (6-25%), weakness (0-10%), dysphagia (0-2%), wheeze/stridor (0-2%).
Podnos et al[281]	Retrospective Cross sectional	100 consecutive lung cancer patients from tumour registry in USA	Case note review	Only 18% asymptomatic at presentation. Mean number of symptoms was 1.9. Most common symptoms at presentation: pain(46%), cough (44%), dyspnoea (37%), fatigue (20%), gastrointestinal symptoms (16.5%) and neurological symptoms (13%).
Lövgren et al[282]	Retrospective review Longitudinal	314 patients with lung cancer First reported symptoms identified then symptoms triggering attendance at doctor identified	Case note review	Most common first reported symptoms: cough (41.8%), fatigue (35.7%), dyspnoea (32.5%), weight loss (32.1%), chest pain (17.7%), anorexia (12.9%), neurological symptoms (10.9%), 3.5 % were asymptomatic. Most common symptoms leading to first attendance at doctor: Cough (27%), dyspnoea (23.8%), chest pain (13.8%) and other pain (8%). More symptoms were reported to be present prior to seeking help than symptoms triggering attendance of the doctor

Kwang et al[173]	Cross sectional	8788 Korean lung cancer patients	Case note review	Prevalence of symptoms at diagnosis: cough(38.1%),dyspnea (24.0%), chest pain (12.1%), haemoptysis (9.2%), 5% or more weight loss during the past several months (9.0%), general weakness(5.7%), and hoarseness (2.2%); 6.5% asymptomatic. Asymptomatic patients received surgery in 60% of cases. Absence of symptoms reduced risk of death from NSCLC when controlled for age, gender, treatment, stage and smoking. No difference found for SCLC.

Table 11: Summary of studies evaluating symptoms at presentation in adults with lung cancer.

New or recent diagnosis				
Investigators	**Design**	**Sample**	**Instruments Utilised**	**Selected Findings**
Mccorkle & Benoliel[182]	Short term Longitudinal Crisis Theory	56 newly diagnosed lung cancer patients 65 patients with recent myocardial infarction Tested 1 and 2 months post diagnosis	Symptom Distress Score (SDS)	Lung cancer patients experienced more symptoms than those with Myocardial infarction. Most patients had little or moderate symptom distress. Most troublesome symptoms were: Fatigue, pain, cough, lack of appetite and insomnia. No difference between 2 times tested.
Kukull et al[181]	Longitudinal	53 newly diagnosed lung cancer patients	SDS McGill Pain Questionnaire	Symptom magnitude may influence survival.
Tishelman et al[164]	Longitudinal	400 newly diagnosed patients with inoperable lung cancer Mean 31 days from diagnosis	Adapted SDS Thurstone Scale of symptom distress-Lung cancer	Most distressing symptoms: dyspnoea, pain & fatigue at baseline, 3 and 6 months. No difference by age, gender or histology. Differences between reported symptom occurrence and symptom distress.
Wennman-Larsen et al[167]	Cross sectional	Dyadic assessment of symptom experience by patients and carer 52 newly diagnosed patients (within 1 month)	EORTC QLQ-C30 and LC13 Carer questionnaire	Significant others rated higher symptom distress than patient. Most distressing symptoms reported by patients: fatigue, cough, pain, dyspnoea and poor appetite. Carers reported: Fatigue, cough, sleep, pain, dyspnoea as most distressing areas. Female carers show greater agreement with patient rated distress.
Cooley et al[174, 283]	Longitudinal Repeated measures Secondary analysis	117 lung cancer patients within 100 days of diagnosis who had received anti-cancer treatment	SDS	Overall most prevalent distressing baseline symptoms were: fatigue (64%), frequency of pain (56%), insomnia (49%), appetite (43%), pain severity (37%). Overall there was a dynamic profile for most prevalent symptom over time. With fatigue and pain being most stable and dyspnoea increasing over time. The 3 most distressing baseline symptoms post surgical patients were: pain, fatigue & insomnia. Majority of symptoms decreased

(continued)				over time except pain and fatigue. For radiotherapy group 3 most prevalent baseline symptoms were: fatigue, appetite & nausea. Most symptoms decreased by 3 month assessment and then increased again. Dyspnoea and cough increased overtime. In chemotherapy group, 3 most prevalent baseline symptoms were fatigue, insomnia and appetite. Combine treatment group: fatigue, frequency of pain and insomnia were most prevalent. Complex dynamic changes over time were observed for individual symptoms. No consistent patient related predictors of symptom distress over time (age, gender, income). Best predictor of 3 and 6 month symptom distress was baseline symptom distress.
Sarna et al[284]	Longitudinal, Descriptive, Correlational	Subsample of 26 adults with newly diagnosed progressive lung cancer	SDS	Average weight change varied little over time. Symptom distress subtle fluctuation.
Degner and Sloan[119]	Cross-sectional	434 newly diagnosed cancer patients Subset of 82 newly diagnosed lung cancer patients	SDS	Patients with lung cancer had greater symptom distress than other cancers. Symptom distress at baseline was predictive of survival. Most common symptoms: fatigue, pain, loss of appetite, cough, insomnia. Females reported more distress than males. Increased distress associated with advanced disease.
Gift et al[285]	Cross sectional Cluster analysis Theory of unpleasant symptoms	220 newly diagnosed lung cancer patients	Structured interview Standardised questionnaire Self designed	Mean of 11 symptoms reported (range 1-27). Common occurring symptoms: fatigue (79%), nocturia (68%), pain (60%) and dyspnoea (58%). Mean symptom severity scores ranged from 1.31 – 2.33 (scale 0-3). No correlation between occurrence and severity of symptoms. Means of most severe symptoms reported: lack of sexual interest (2.07), vomiting (2.00), trouble sleeping (1.89), fatigue (1.84),

(continued)				pain (1.84) & dyspnoea (1.82). No consistent clustering of symptoms found. Increased symptom occurrence and severity in those with co-morbid conditions.
Khalid et al[104]	Cross sectional	29 Lung cancer patients presenting at secondary care setting Compared to new diagnosis gastrointestinal cancer patients Specific focus on symptoms that may reduce calorie intake	Patient-generated subjective global assessment tool Self designed Case note review	66% of lung cancer patients reported at least one symptom. Significantly more reported anorexia in lung cancer patients. No other major differences in reported symptoms. Increased prevalence of symptoms in advanced disease.
Lövgren et al[286]	Longitudinal	159 Inoperable lung cancer patients from diagnosis, through treatment at 1 and 3 months	EORTC QLQ-C30+Lung cancer module 13 (LC13)	Prevalence of main symptoms at diagnosis were: tiredness (88%), depression (86%), worry (83%), dyspnoea (79%), cough (74%), insomnia (63%), anorexia (56%), pain (56%). Most distressing symptoms were: fatigue, dyspnoea, cough, pain and insomnia. There were some differences between men and women. Prevalence of main symptoms at 3 months were: Tiredness (93%), weakness (84%), reduced PS (81%), dyspnoea (74%), depressed (66%), pain (55%), anorexia (53%).

Table 12: Summary of studies evaluating symptoms in new or recently diagnosed adults with lung cancer.

Established diagnosis of lung cancer and/or have received anti-cancer treatments				
Investigators	**Design**	**Sample**	**Instruments Utilised**	**Selected Findings**
De Maria and Cohen[287]	Cross sectional subanalysis	1395 established diagnosis lung cancer patients	Standard Assessment tool Self designed registry data	Symptom prevalence overall: cough (54%), weight los (50%). Dyspnoea (36%), chest pain (32%), hoarseness (8%) and Dysphagia (3%). Analysis of age groups (40-50, 51-69 & >70 years). Elderly group reported more presenting dyspnoea but less pain. Only 10% asymptomatic in any age group. No differences in weight loss. Co morbidity present in 44% of elderly population and only 25% of <70 year olds.
Kaasa et al[288]	RCT Longitudinal	95 patients with NSCLC undergoing treatments (51 radiotherapy, 44 chemotherapy)	Toxicity Questionnaire Self-designed (10 Questions)	Main symptoms insomnia, pain, tiredness and anorexia in both groups. Nausea, vomiting and hairloss common in chemotherapy group. Dysphagia and sore throat common in radiotherapy group.
Muers & Round[289]	Longitudinal	289 patients with NSCLC 64 post surgery 122 post radiotherapy 103 supportive care	Standard Assessment Tool Self designed	Most common symptoms at presentation were: Cough (79%), dyspnoea 75%), chest pain (37%), anorexia(45%) and fatigue(45%). Most symptoms worsened with time (pain, dyspnoea, malaise & anorexia).
Sarna[284]	Cross sectional	69 Females with lung cancer 43% receiving treatment	SDS	Most patients experienced more than one symptom (61%). Most common symptoms: fatigue, pain and insomnia. Higher symptom distress associated with comorbidity, low income, previous chemotherapy and no surgery.
Sarna et al[290]	Longitudinal	Subsample of 60 adults with advanced lung cancer. 50% receiving chemotherapy	SDS	Pre-illness weight loss moderately correlated with decrease in PS.
Furuta et al[291]	Retrospective Longitudinal	240 NSCLC before receiving radiotherapy	Not specified Chart review	Only 15% asymptomatic before treatment. Symptoms not an independent predictor of survival. Symptoms closely correlated with stage and PS. Common symptoms: cough (68%), haemoptysis (35%), chest pain (20%), dyspnoea (17%), fatigue (5%).

Hopwood & Stephens[292]	Cross sectional	655 patients with lung cancer 232 SCLC receiving chemotherapy 423 NSCLC receiving chemotherapy	Adapted Rotterdam Symptom Checklist	Most common symptoms at presentation: Tiredness, lack of energy, worry, anxiety, cough, dyspnoea, anorexia & insomnia SCLC reported more symptoms (mean 17) than NSCLC (mean 13) and also more severe symptoms. Most symptoms persisted beyond treatment end. Females reported more psychological symptoms than males.
Lutz et al[293]	Retrospective Case notes review	54 patients with NSCLC who had received palliative radiotherapy	Observer component of the LCSS	96% patients presented with at least 1 symptom. (Median 2.3 symptoms). Common moderate to severe symptoms: dyspnoea (55%), anorexia (28%), cough (21%), pain (14%) and fatigue (12%) 65% of patients had post radiotherapy improvement in some symptoms. Main symptoms palliated were cough, haemoptysis and dyspnoea Fatigue worsened post radiotherapy Only 2 % gained complete palliation.
Sarna & Brecht[294]	Cross sectional	60 Females with advanced lung cancer receiving palliative treatments	SDS	Mean number of symptoms 3.2 (Range 0-12). Most common serious symptoms: fatigue (56.7%), outlook (38.3%), pain frequency (367%), insomnia (28.3%) and cough (21.7%). Some symptoms could be grouped but complex reasons for groupings probable.
Stephens et al[295]	Longitudinal	810 patients with advanced lung cancer within chemotherapy and radiotherapy clinical trials	Adapted Rotterdam Symptom Checklist Clinical reports	78% agreement in symptom occurrence assessment between doctors and patients. Doctors underestimated symptom severity. Increasing disparities as severity increased. In chemotherapy group commonest symptoms: cough (67%), alopecia (60%), anorexia (56%), hoarse voice (46%), chest pain (43%) & numbness (43%). In radiotherapy group: cough (84%), chest pain (56%), anorexia (49%), hoarse voice (33%), numbness (27%) & nausea (25%).

Erridge et al[296]	RCT of 2 palliative radiotherapy regimens	149 patients with lung cancer who presented with cough, haemoptysis, dyspnoea, chest pain or dysphagia (Total eligible population for study not known)	Standard assessment score Self designed Spitzer's QOL index HADS	Improvement in total symptom score in 77% with single fraction and 92% in 10 fraction group. Complete resolution in 5% in single fraction group and 23% in 10 fraction group. 41and 49% patients experienced fatigue in single and 10 fration groups respectively. 30 and 34% patients experienced nausea or vomiting respectively Anxiety and depression in around 50% of patients.
Kurtz et al[111]	Longitudinal	129 lung cancer patients older than 65 years Treatments noted Subanalysis of wider study of all cancer types	Symptom experience scale	No significant differences in severity of symptoms between treatment, gender and stage groups. Symptom severity was predictor of loss of function. Most common symptoms: fatigue (82.2%), cough (67.4%), nocturia (65.9%), dyspnoea (61.2%), pain (58.9%) and weakness (55%).
Lutz et al[297]	Longitudinal	69 lung cancer patients with locally advanced disease at radiotherapy centre	The lung cancer symptom scale	All patients had at least one symptom at referral, 79% 3 or more symptoms. Most common symptoms at referral were: Fatigue (80%), cough (77%), dyspnoea (73%), appetite (65%) and chest pain (57%) All symptoms increased in prevalence in 0-3months prior to death compared to 4-6 month prior to death. Symptom severity and distress was higher in those surviving shortest.
Oh[114]	Cross sectional	106 lung cancer patients from in-patient respiratory and oncology units in Korea	Korean translation of SDS	Mean symptom severity of 32.74. Means of most severe symptoms: anorexia (3.13), fatigue (2.97), outlook (2.76) and cough (2.74). Symptom distress was not related to age, gender or histology Significantly more distress in those with advanced stage compared to early stage lung cancer. No difference between surgery, chemotherapy and radiotherapy for mean symptom distress. More symptom distress in group not receiving anti-cancer treatments. Trend less symptoms in older age group.

Gift et al[298]	Longitudinal Cluster analysis Secondary analysis Theory of unpleasant symptoms	112 lung cancer patients who had survived at least 6months from diagnosis Looked at symptom cluster of: fatigue, weakness, nausea, vomiting, anorexia, weight loss and dysguesia	Physical Symptom assessment tool	Cluster of symptoms at baseline remained at 3 & 6 months. Mean number and severity of symptoms declined over time. Baseline severity of individual symptoms did not usually correlate with severity later. No association between treatments, gender, age or co morbidity with number of reported symptoms. Advanced staging at diagnosis did predict increased symptoms Symptom distress was predictive of prognosis. For each additional unit of severity score, the odds of dying increased by 33%.
Wang et al[299]	Cross sectional Cluster analysis	108 lung cancer patients from oncology out-patients in Taiwan	MD Anderson Symptom Inventory translated into Taiwanese	Most common symptoms were: fatigue, insomnia, poor appetite, dyspnoea and 'distress'. 2 major symptom clusters identified of gastrointestinal symptoms and general symptoms.

Table 13: Summary of studies evaluating symptoms in adults with established lung cancer and/or receiving anti-cancer treatment.

Palliative or supportive care settings				
Investigators	**Design**	**Sample**	**Instruments Utilised**	**Selected Findings**
Krech et al[300]	Cross sectional	100 lung cancer patients referred to palliative care service	Standard Assessment Tool Self designed (Used within service)	Median number of symptoms was 9 (Range 1-23). Most common symptoms were: pain (86%), dyspnoea (70%), anorexia (68%), constipation (52%), fatigue (52%). Depression in 34% and Anxiety in 27%. No gender differences in symptoms. Some age differences. 62% of reported symptoms were moderate-severe. Trend that number of symptoms increased in patients with lower performance status.
Vainio & Auvinen[301]	Cross sectional	1640 patients with advanced cancer referred to palliative care service 387 lung cancer patients	Standardised Assessment Tool Self designed	Most common symptom in lung cancer patients: weakness (60%), pain (52%), weight loss (49%), dyspnoea (46%) anorexia (35%).
Lobchuk et al[168]	Cross sectional	37 adults with lung cancer and caregivers from palliative care service or out-patient oncology service	SDS	Patients rated top 6 most distressing symptoms as: fatigue, cough, pain (frequency), outlook and insomnia. Carers rated top 6 most distressing symptoms as: fatigue, outlook, insomnia, cough, pain (frequency), dyspnoea. Carers rated distress higher than patients (global distress and most individual symptoms). Agreement was greater for symptoms rated most distressing by patients.
Lobchuk & Kristjanson[176]	Cross sectional	37 adults with lung cancer and caregivers from palliative care service or out-patient oncology service Extended qualitative analysis	SDS Behavioural cues assessment	Caregivers use behavioural and verbal cues to assess symptom distress. Behavioural observation did not reduce assessment discrepancies.

Edmonds et al[178]	Retrospective structures interviews with bereaved carers	449 lung cancer patients' post-bereavement carers Compared to 87 chronic lung disease post-bereavement carers	Structured interviews	Mean number of symptoms in last year of life 6.9. Last year life most distressing symptoms in lung cancer: Pain(85%), dyspnoea (78%), anorexia (76%), mood (68%), cough (56%), insomnia (60%), constipation (59%), low sickness(46%), Mean number of symptoms in last week of life 5.6. In last week of life most distressing symptoms: anorexia (70%), dyspnoea (69%), pain (64%), low mood (49%), mouth problems (46%), cough (40%), insomnia (40%). Chronic lung disease patients post-bereavement carers reported comparable levels of symptom distress to lung cancer.
Henoch et al[302]	Longitudinal	106 patients with incurable lung cancer not under-taking life prolonging treatments	Assessment of quality of life at the end of life tool Cancer dyspnoea scale HADS	Mean dyspnoea scores increased over time. HADS depression and anxiety scores increased over time (only depression saw significant increase). QOL scores reduced over time. QOL score correlated strongly with anxiety and depression and moderately with PS, pain and dyspnoea. No significant correlation between QOL and gender, histology or occurrence of metastases.
Skaug et al[303]	Retrospective Cross sectional	247 of 253 lung cancer deaths examined Last 8 weeks of life examined	Standardised scale Self designed Case note review	Prevalence of main symptoms in last 8 weeks of life: pain (85%), dyspnoea (54%), cough (28%), nausea (27%), haemoptysis (9%), psychological symptoms (71%) and neurological symptoms (28%). 99% of patients had at least one symptom. Gender and initial PS did not predict any specific symptom occurrence. No significant difference in physical symptoms across age groups.

Table 14: Summary of studies evaluating symptoms in adults with lung cancer in palliative or supportive care settings.

Longer Term Survivors				
Investigators	**Design**	**Sample**	**Instruments Utilised**	**Selected Findings**
Fox & Lyon[304]	Cross sectional Correlational Cluster analysis	51 Norwegian lung cancer patients subset from previous QOL study Recruited from an internet based support group Full range of self-reported stages	Shortform 36 health status survey (SF-36) Fox simple QOL Sclae	Participants on average diagnosed 32 months prior to study 50% had undergone surgery (Atpyical for lung cancer) 93% patients reported at least 'a little bit' depression, fatigue & pain. Most severe symptom was fatigue. Depression correlated with fatigue. Fatigue correlated with pain. Depression and fatigue, but not pain, negatively correlated with QOL.

Table 15: Summary of studies evaluating symptoms in survivors with lung cancer.

5.2.1 Design of Studies

Nineteen (48.7%) studies used a longitudinal design; 17 (43.5%) used a cross-sectional design. Of the other three (7.8%) studies, one was a review of eight studies prior to 1997 evaluating symptoms at time of presentation,[66] one was a retrospective case-control study of symptoms at initial presentation to primary care[82] and the final study was a qualitative exploration of symptoms in the last year of life of lung cancer patients and chronic obstructive pulmonary disease (COPD) patients. This study used structured interviews with bereaved relatives to construct a picture of symptoms in the last year of life of the deceased patient.[178] Of those focused on new or recent diagnosis, eight were longitudinal and five cross-sectional. Those focusing on treatment phase included nine longitudinal designs and seven cross-sectional. As noted in the previous review, there was a wide range of follow-up time in the longitudinal studies, ranging from a few weeks[303] to five years.[291]

5.2.2 Samples and Phase of Lung Cancer Journey Evaluated

Five studies considered symptoms at point of presentation or prior to presentation,[66, 82, 173, 281, 282] ten studies evaluated the newly diagnosed phase of the journey,[164, 167, 181, 182] 16 reported on the treatment phase,[111, 114, 115, 120, 284, 287, 289-299] seven on patients receiving supportive care, palliative care or end of life care[168, 176, 178, 300-303] and one on survivors of lung cancer.[304] These articles did overlap and there was not always a clear distinction between phases. In particular, several studies evaluated from diagnosis through treatment. Sample sizes varied from 26[305] to 8788 patients.[173]

5.2.3 Tools for Symptom Measurement

Within this review of lung cancer symptom assessment, several different tools have been utilised. Four studies used a case note review to determine presence and severity of symptoms, two studies used qualitative interviews, one study used a self-designed toxicity questionnaire and seven utilised standardised questionnaires or scales designed by the authors or already being used within the clinical setting. The other studies used recognised, or adapted, symptom assessment tools including: Symptom Distress Scale[201] ((SDS) n=10), McGill Pain Questionnaire[306] ((MPQ) n=1), European Organisation for Research and Treatment of Cancer Quality of Life Score[198] (EORTC QLQ-C30) with lung cancer module 13[203] ((LC13) n=2), Rotterdam Symptom Checklist[307] ((RSCL) n=2), Lung Cancer Symptom Scale[202] ((LCSS) n=2), Symptom

Experience Scale[308241] ((SES) n=1), MD Anderson Symptom Inventory[309] ((MDASI) n=1), Hospital Anxiety and Depression Score[310] ((HADS) n=1), Assessment of Quality of Life at the End of Life[311] ((AQEL) n=1) and Shortform 36 Health Status Survey[312] ((SF-36) n=1). The SDS was the most common instrument. This 13 item self-report tool provides a measure of symptom distress defined as 'the degree of discomfort being experienced as reported by the patient'. Eleven of the items are assessed on a five point Likert-type scale, ranging from 1 (indicating normal) to 5 (representing extreme distress such as nausea, insomnia, appetite, pain, fatigue, bowel pattern, concentration, appearance, outlook, breathing and cough). The final two items assess frequency of nausea and pain. A summated score ranging from 13 to 65 evaluates 'global symptom distress'. It is of note that this tool was adapted by Tishelman et al,[164] arguing that it actually assessed symptom occurrence rather than distress because patients are asked to primarily rate intensity and frequency. The adaptations explicitly rated intensity, frequency and distress as separate considerations.

5.3 Discussion

Weisman and Worden first reported the high symptom burden in lung cancer in 1976 in their study evaluating symptom distress in 163 adults newly diagnosed with a variety of cancers. The peak levels of emotional distress occurred within the first 100 days after diagnosis and were highly correlated to the number of physical symptoms.[4]

Degner and Sloan[119] utilised the Symptom Distress Scale[182, 201] (SDS) to evaluate symptoms in a consecutive sample of 434 newly diagnosed cancer patients over six months from diagnosis. The 83 lung cancer patients in this study experienced significantly more symptom distress than the other cancer types included. Furthermore, symptom distress at diagnosis correlated with reduced overall survival from diagnosis.[119] McCorkle and Benoliel[182] compared symptoms in newly diagnosed lung cancer patients to those with a recent myocardial infarction. At one and two months after diagnosis, lung cancer patients reported significantly higher levels of symptom distress.

In one study comparing palliative care needs of patients dying with chronic respiratory disease and lung cancer, Edmonds et al[178] found no overall difference in mean number of symptoms between the two groups. There were differences in specific symptoms with significantly more dyspnoea in those with chronic respiratory disease but more

anorexia and constipation in the lung cancer patients. It is of note that up to 22% of lung cancer patients in a population-based study in the Netherlands had co-existent chronic obstructive pulmonary disease (COPD). In a recent unpublished prospective audit quantifying co-morbidity in lung cancer patients in Scotland, COPD was found to be co-existent in around 45% of lung cancer patients and around 50% of patients from the site of this study (Stobhill Hospital, Glasgow).[189] It is not surprising that there may be site-specific symptoms which are more prevalent in specific cancers than others, such as dyspnoea in lung cancer.[301] However, there may also be a high generalised burden of systemic symptoms, such as loss of appetite and fatigue, in lung cancer that is greater than in other cancer types.[104]

At presentation, 90% of lung cancer patients report at least one symptom.[81] There have been a variety of studies examining the prevalence of symptoms within the lung cancer population but relatively few of these studies evaluated symptoms at initial presentation. Table 3 outlines the wide range of potential presenting symptoms previously reported. Khalid et al[104] surveyed newly diagnosed lung cancer patients to assess symptoms that may reduce nutritional intake and found that 66% of lung cancer patients presented with symptoms with an increased prevalence between locally advanced and metastatic disease. The most prevalent symptoms were: loss of appetite (58%), nausea (30%), early satiety (21%), xerostomia (17%) and pain of any site (12%).

The more recently published large, cross-sectional study by Kwang et al[173]details the symptoms at presentation of 8788 Korean patients diagnosed with lung cancer. Only 6.5% of cases had no symptoms on presentation

Symptoms and Signs at Presentation	Range of Frequency Previously Reported[66] (%)	Frequency of Symptoms Reported (%) Kwang et al[173]
Cough	8-75	38.1
Weight Loss	0-68	9
Dyspnoea	3-60	24
Chest Pain	20-49	12.1
Haemoptysis	6-35	9.2
Bone Pain	6-25	-
Clubbing of fingers	0-20	-
Fever	0-20	-
Weakness	0-20	5.7
SVCO	0-4	-
Dysphagia	0-2	-
Wheezing or Stridor	0-2	-
Hoarseness	-	2.2%
Asymptomatic	-	6.5%

Table 16: Comparison of symptom prevalence previously recorded[66] and by Kwang et al.[173]

The assessment of symptoms will be influenced by the method used. The large study by Kwang et al[173] found there was a wide range of symptom prevalence reported. The most common symptoms tended to include fatigue, pain, cough, dyspnoea, insomnia and loss of appetite. It should be noted that pain, fatigue and anorexia were also commonly reported symptoms.[183] In Cooley's systematic review[1] of symptoms in lung cancer patients in 2000, three studies evaluating newly diagnosed patients were noted. The most commonly reported symptoms in these studies were fatigue, pain, cough, lack of appetite and insomnia.[119, 181, 182] Cooley[1] noted that two separate studies using the SDS in newly diagnosed lung cancer patients, conducted in different countries and at different times, have reported the symptoms as the most common. More strikingly, the mean score on the SDS was similar in both the described studies.[119, 182] Furthermore, Cooley went on to use the SDS to assess newly diagnosed lung cancer patients (within 100 days) and found the most prevalent distressing symptoms again included: fatigue (64%), frequency of pain (56%), insomnia (49%), anorexia (43%) and severity of pain (37%). Few tools ask specifically about sexual dysfunction,[183] but in the study by Gift et al[285] mean score of 'lack of sexual interest' was reported as the highest rated severe symptom.

In patients undergoing treatment, the additional element of treatment-related symptoms is introduced. The majority of studies evaluating patients in the treatment phase consider those actively receiving treatment or those at treatment completion. Further complexity is introduced by recognising that many of the treatments being delivered are targeted against specific symptoms, such as radiotherapy[313] to palliate pain, cough or haemoptysis or chemotherapy[314] to palliate pain and other symptoms. Thus, there is a dynamic interplay between host, disease and treatment relating to the global symptom burden. Again, design of the instrument influences the reported symptoms, and some studies target the questions against known toxicities of the treatment being received.[288]

5.3.1 Quality of Life and Symptoms in Lung Cancer

When a treatment does not improve survival, then it is recommended that the primary goal becomes quality of life (QOL) improvement.[315, 316] Despite this goal, no precise definition of QOL has been agreed upon and working definitions vary widely within the literature.[317] Broadly, QOL can be considered as a global 'well-being' concept defined as a 'subjective evaluation of life as a whole',[121] or it can be considered 'well-being' when related to health or illness.[318] The latter definition is referred to as 'health-related

quality of life'(HRQOL).[319] HRQOL may also be considered as a component of global QOL.[318] Some authors classify definitions of QOL as based on 'functional status', 'subjective well-being' or a combination of both.[317] QOL can be globally rated or broken into domains and sub-domains. There is disagreement within the literature whether domains can subsequently be summated to provide a valid global score.[317]

Concepts closely related to QOL include: functional status, life satisfaction, well-being, health status and needs. Within the literature there is overlap in the use of definitions of these concepts with QOL. Increased ambiguity can occur as some authors interchange the term QOL with some of these other concepts.[320] As QOL research progresses, there are some points of consensus developing: QOL cannot be equated to patients' objective circumstances; QOL is multidimensional and QOL should be assessed from the perspective of the patient.[321] Assessment of objective factors does not consistently equate to predictable QOL; each individual's QOL relates to their particular situational factors (i.e. the psychosocial context they live within) and internal factors (i.e. their own psycho-emotional state, experiences, expectations and beliefs). Although there is agreement that QOL is multidimensional, the nature of those dimensions is debated. Most authors would agree that there are four main dimensions to HRQOL: physical, functional, emotional and social. Other dimensions of importance may include: spirituality, sexuality, cognitive function[311] and economic factors.[53, 320]

Assessment of QOL relates to patient rating of either a global QOL or of domains or sub-domains. There are many tools available for assessing QOL in cancer and in lung cancer, and although many of these contain physical symptom components,[322] they differ from symptom (or symptom distress) assessment and needs assessment. Symptom burden may predict overall QOL,[121, 323] but it is not clear if this is an independent effect or if it relates to the functional effects of symptoms.[172] In some chemotherapy trials, global QOL has not changed, but symptom burden measures do show a response to treatment (recognising the possible interplay between treatment-related symptoms, improved disease-related symptoms or worsening disease-related symptoms).[324] It may be that symptom burden is an adequate outcome measure to allow service providers, patients and clinicians to make decisions about specific treatments in the future.[324]

5.3.2 Symptoms, QOL and Prognosis in Lung Cancer

Symptoms may be predictive of mortality in cancer.[1, 183, 309] In the advanced cancer setting, it is clear that the symptoms of anorexia, dyspnoea, xerostomia, weight loss and delirium are adverse prognostic factors for lung cancer and for other advanced cancers.[132-136]

In lung cancer there is specific evidence of a relationship between increased symptom distress and worse survival. Degner and Sloan's[119] analysis of 82 lung cancer patients in a wider cohort of 434 ambulatory, newly diagnosed cancer patients showed a significant negative correlation between symptom distress (measured by the symptom distress scale) and survival. This relationship held true when symptom distress was measured any time in the six months following diagnosis. However, the authors reported three patients with high symptom distress but greater than five years' survival. On further review, these patients had undergone thoracotomies and had significant post-surgical pain at time of testing. This was noted as a limitation of symptom assessment for aiding prognostication. Kasaa et al[120] had previously found inoperable lung cancer patients with low symptom distress survived longer than those with higher levels of distress, irrespective of treatment. Kukull et al[181] also found a negative correlation with higher symptom distress (measured by the symptom distress scale) and survival when controlled for age, personality factors and functional status. These studies using the same assessment tool found the most frequently distressing symptoms to be fatigue, pain, loss of appetite and insomnia.

It has recently been reported that Korean patients with lung cancer who were asymptomatic at presentation survived longer than those who were symptomatic at presentation.[173] In this large national survey of 8788 patients diagnosed with lung cancer in 2005, only 6.5% presented with no symptoms. Sixty percent of asymptomatic patients underwent curative intent surgery. Furthermore, those asymptomatic patients with NSCLC had reduced risk of death from lung cancer regardless of age, gender, stage at diagnosis, smoking history and whether treatment was performed. Interestingly, this was not the case for the asymptomatic patients with SCLC in this cohort.[173] Global QOL or domains from within QOL assessment may also be an independent predictor of mortality in lung cancer at different stages of disease.[115, 117, 120, 325-331]

5.4 Conclusions

Lung cancer patients face a high symptom burden throughout their cancer journey. Symptoms can be caused by the disease, treatments or comorbidities. Most patients experience a high number of different symptoms, commonly including dyspnoea, pain, fatigue, anorexia, weight loss and psychological distress. These individual symptoms and their combination can lead to severe symptom distress in many lung cancer patients.

6 Results

6.1 Evaluation of Lung Cancer Population Attending the Stobhill Lung Cancer Clinic

The multidisciplinary lung clinic provides care for patients at different times within their cancer journey. The characteristics of patients who completed a questionnaire were evaluated and compared to national audit data.[332] Methods have been described in Section 3.

6.1.1 Number of Patients Participating

A total of 391 patients attending the multidisciplinary lung clinic completed at least one questionnaire (frequencies of Q1 in complete sample). Of these patients, 353 had a known diagnosis of lung cancer (either histological or clinico-radiological). Of the remaining 38 patients, 13 had a confirmed diagnosis of mesothelioma and 25 had either an alternative diagnosis or no confirmed diagnosis. In this group of 25 patients, the alternative diagnoses included: metastatic breast, colon and renal cancer, resolving pneumonias, tuberculosis, and pleural plaques only.

6.1.2 Questionnaire Response and Timing

Each patient could complete the questionnaire several times over the duration of their clinic attendances. Over the 30 month study period 862 questionnaires were returned by 353 lung cancer patients, 219 patients completed greater than one questionnaire, 353 questionnaires (41.1%) were initial questionnaires (Q1) and (219) 25.3% of questionnaires were the second returned (Q2). The time between each serial questionnaire is tabulated below for between Q2 and Q1, Q3 and Q2, Q4 and Q3, and Q1 and QF (when more than one questionnaire was completed; see Table 17). On average, each patient completed two questionnaires ($\bar{x}$=2.29, SD=1.57; median 2, range=1-11; see Table 18).

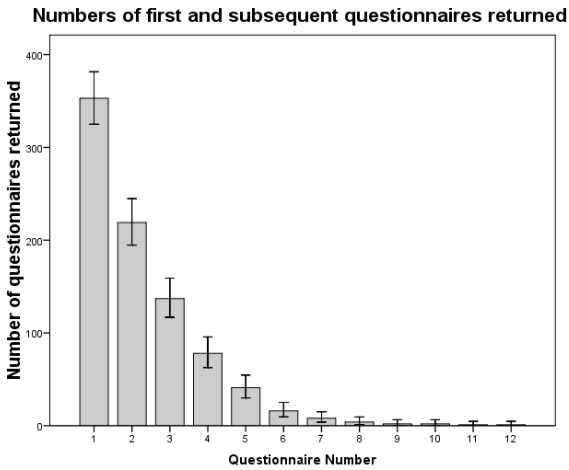


Figure 8: Bar chart of numbers of Q1 to Q12 returned (with 95% confidence intervals).

	Time between Q2 and Q1		Time between Q3 and Q2		Time between Q4 and Q3		Time between QF and Q1	
Mean (SD) in days	100.13 (91.78)		114.77 (100.778)		113.74 (89.786)		237.34 (198.35)	
Median (Range) in days	77 (0-644)		91 (0-546)		91 (7-392)		182 (7-826)	
	Number	Percentage	Number	Perentage	Number	Percentage	Number	Percentage
Total	216	98.6%	132	96.4%	76	97.4%	213	97.3%
< 4 weeks	41	18.7%	19	13.9%	12	15.4%	13	5.9%
4-8 weeks	45	20.5%	18	13.1%	13	16.7%	28	12.8%
2-4 months	73	33.3%	55	40.1%	23	29.5%	46	21.0%
>4 months	57	26.0%	40	29.2%	28	35.9%	126	57.5%
Missing	3	1.4%	5	3.6%	2	2.6%	6	2.7%

Table 17: Time between serial questionnaires and between first (Q1) and final (QF) questionnaires.

One questionnaire only was completed by 134 patients; the first questionnaire was, therefore, their final questionnaire (QF). For these patients, their final questionnaire was coded as 'QF=Q1' (see Table 18).

Number of questionnaire	Frequency of each questionnaire	Percentage of total number of questionnaires	Number of patients when Qx = QF	Percentage of total number of questionnaires
First	353	41	134	15.5
Second	219	25.4	82	9.5
Third	137	15.9	59	6.8
Fourth	78	9	37	4.3
Fifth	41	4.8	25	2.9
Sixth	8	1.9	8	0.9
>6	18	2	8	0.9

Table 18: Number and percentages of questionnaires returned within study period.

6.1.3 Questionnaire Response and Timing

An overall analysis of the characteristics of the population attending the lung cancer clinic was carried out utilising Q1 as the index questionnaire. Overall staging and presence of metastatic disease was tabulated (Table 19). Overall survival and median survival have been calculated and plotted using Kaplan-Meier survival curves (Figure 9 and Table 20). The characteristics of patients with lung cancer were tabulated by gender (Table 21).

	All patients (n=353)		Recent diagnosis (Q1within 6 weeks) (n=170)		Died within 3 months of QF completion (n=121)	
	Number	%	Number	%	Number	%
NSCLC or clinical lung cancer						
Stage						
1A	24	6.8%	3	1.8%	1	0.8%
1B	48	13.6%	17	10.0%	7	5.8%
2A	21	5.9%	11	6.5%	6	5.0%
2B	20	5.7%	5	2.9%	2	1.7%
3A	28	7.9%	18	10.6%	6	5.0%
3B	71	20.1%	34	20.0%	31	25.6%
4	87	24.6%	54	31.8%	46	38.0%
Unknown	8	2.3%	4	2.4%	1	0.8%
SCLC						
Stage						
Limited	17	4.8%	9	5.3%	6	5.0%
Extensive	27	7.6%	15	8.8%	15	12.4%
Unknown	2	0.6%	0	0.0%	0	0.0%
Metastatic or not						
No known metastases	239	67.7%	101	59.4%	60	49.6%
Metastatic disease	114	32.3%	69	40.6%	61	50.4%

Table 19: Overall numbers and percentages of stage and metastatic status of all patients, newly diagnosed patients and those who died within three months of completing QF.

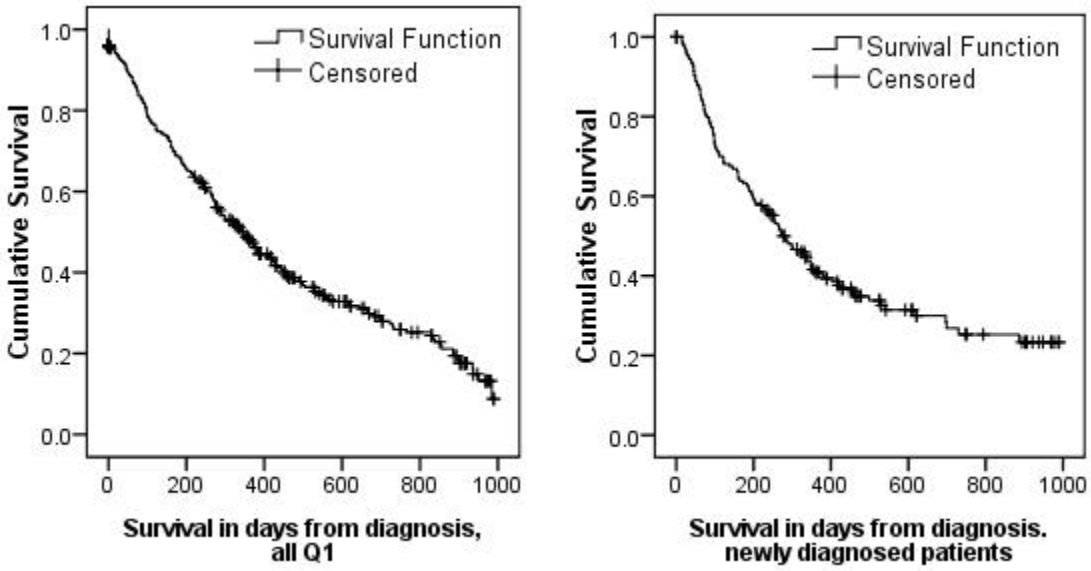


Figure 9: Kaplan-Meier survival curves for all patients attending the lung cancer clinic (new and return patients) and all newly diagnosed patients.

				95% Confidence interval	
	Median Survival (Days)	Median survival (Months)	Standard error	Lower	Upper
All patients	344	11.47	27.10	290.89	397.11
Newly diagnosed	274	9.13	34.09	207.19	340.81

Table 20: Median overall survival (95% confidence intervals) for all patients and newly diagnosed patients.

Charcteristics of lung cancer patients by Gender

	Males		Females		Total	
	Number	%	Number	%	Number	%
All Patients	174	49.3%	179	50.7%	353	100.0%
Year one	88	24.9%	89	25.2%	177	50.1%
Year two	53	15.0%	56	15.9%	109	30.9%
Year three	33	9.3%	34	9.6%	67	19.0%
Age						
50 years and less	7	2.0%	3	0.8%	10	2.8%
51-69 years	83	23.5%	82	22.9%	165	46.5%
70 years and more	84	23.8%	95	26.9%	179	50.7%
Unknown	0	0.0%	0	0.0%	0	0.0%
Vital Status	174	49.3%	179	50.7%	353	100.0%
Alive	58	16.4%	79	22.4%	137	38.8%
Dead: cause lung cancer	104	29.5%	81	22.9%	185	52.4%
Dead: cause not lung cancer	3	0.8%	9	2.5%	12	3.4%
Dead: cause unknown	9	2.5%	10	2.8%	19	5.4%
Histology	174	49.3%	179	50.7%	353	100.0%
NSCLC	126	35.7%	114	32.3%	240	68.0%
Stage 1A	6	1.7%	16	4.5%	22	6.2%
Stage 1B	24	6.8%	15	4.2%	39	11.0%
Stage 2A	5	1.4%	8	2.3%	13	3.7%
Stage 2B	13	3.7%	4	1.1%	17	4.8%
Stage 3A	9	2.5%	9	2.5%	18	5.1%
Stage 3B	34	9.6%	23	6.5%	57	16.1%
Stage 4	33	9.3%	35	9.9%	68	19.3%
Unknown Stage	2	0.6%	4	1.1%	6	1.7%
SCLC	20	5.7%	26	7.4%	46	13.0%
Limited	9	2.5%	8	2.3%	17	4.8%
Extensive	10	2.8%	17	4.8%	27	7.6%
Unknown Stage	1	0.3%	1	0.3%	2	0.6%
CLC	28	7.9%	39	11.1%	67	19.0%
Stage 1A	0	0.0%	2	0.6%	2	0.6%
Stage 1B	4	1.1%	5	1.4%	9	2.5%
Stage 2A	2	0.6%	6	1.7%	8	2.3%
Stage 2B	1	0.3%	2	0.6%	3	0.8%
Stage 3A	3	0.8%	7	2.0%	10	2.8%
Stage 3B	6	1.7%	8	2.3%	14	4.0%
Stage 4	10	2.8%	9	2.5%	19	5.4%
Unknown Stage	2	0.6%	0	0.0%	2	0.6%
PS at diagnosis assessed by doctor	152	43.2%	156	44.1%	308	87.3%
0	18	5.1%	12	3.4%	30	8.5%
1	87	24.6%	100	28.4%	187	53.0%
2	38	10.8%	43	12.2%	81	22.9%
3	9	2.5%	1	0.3%	10	2.8%
4	0	0.0%	0	0.0%	0	0.0%
Unknown	22	6.2%	23	6.5%	45	12.7%
Current PS, rated by patient	163	46.1%	170	48.2%	333	94.3%
0	25	7.1%	26	7.4%	51	14.4%
1	64	18.1%	57	16.1%	121	34.3%
2	33	9.3%	35	9.9%	68	19.3%
3	35	9.9%	46	13.0%	81	22.9%
4	6	1.7%	6	1.7%	12	3.4%
Unknown	11	3.1%	9	2.5%	20	5.7%
Deprivation Category	171	48.4%	176	49.9%	347	98.3%
1 *most affluent*	0	0.0%	1	0.3%	1	0.3%
2	15	4.2%	21	5.9%	36	10.2%
3	15	4.2%	13	3.7%	28	7.9%
4	25	7.1%	9	2.5%	34	9.6%
5	29	8.2%	34	9.6%	63	17.8%
6	11	3.1%	11	3.1%	22	6.2%
7 *least affluent*	76	21.5%	87	24.6%	163	46.2%
Could not determine	3	0.8%	3	0.8%	6	1.7%
Deprivation Decile	171	48.4%	176	49.9%	347	98.3%
1 *most affluent*	5	1.4%	3	0.8%	8	2.3%
2	10	2.8%	19	5.4%	29	8.2%
3	9	2.5%	4	1.1%	13	3.7%
4	6	1.7%	8	2.3%	14	4.0%
5	2	0.6%	1	0.3%	3	0.8%
6	12	3.4%	4	1.1%	16	4.5%
7	17	4.8%	14	4.0%	31	8.8%
8	23	6.5%	25	7.1%	48	13.6%
9	5	1.4%	6	1.7%	11	3.1%
10 *least affluent*	82	23.2%	92	26.1%	174	49.3%
Could not determine	3	0.8%	3	0.8%	6	1.7%
Time of Q1 from diagnosis	174	49.3%	179	50.7%	353	100.0%
< 3 weeks	53	15.0%	64	18.1%	117	33.1%
3-6 weeks	31	8.8%	22	6.2%	53	15.0%
6 weeks to 3 months	19	5.4%	15	4.2%	34	9.6%
3-6 months	22	6.2%	21	5.9%	43	12.2%
6-12 months	21	5.9%	19	5.4%	40	11.3%
>12 months	25	7.1%	37	10.5%	62	17.6%
Q1 preceded diagnosis	2	0.6%	0	0.0%	2	0.6%
Not known	1	0.3%	1	0.3%	2	0.6%

Table 21: Characteristics of lung cancer patients by gender.

Within this population, there were slightly more females (50.7%) than males (49.3%). The mean age of patients was 69.3 years (SD 9.12 years). There was no significant difference in mean age between genders (p=0.192, Student's t test). The majority of patients had NSCLC (68%), 13% were diagnosed with SCLC and 19% with clinico-radiological lung cancer. There were no significant overall differences between genders (X^2=3.118, df=2, p=0.21). No patient had a doctor assessed PS of 4 at diagnosis. PS=4 was self-rated by 12 (3.4%) patients. There was no significant difference between gender for self-rated PS (X^2 =1.831, df=4, p=0.767).

There was a high level of deprivation within this lung cancer population. The majority (52.4%) of patients were in the two most deprived Carstairs deprivation categories ('1' least deprived, '7' most deprived; see Figure 10).

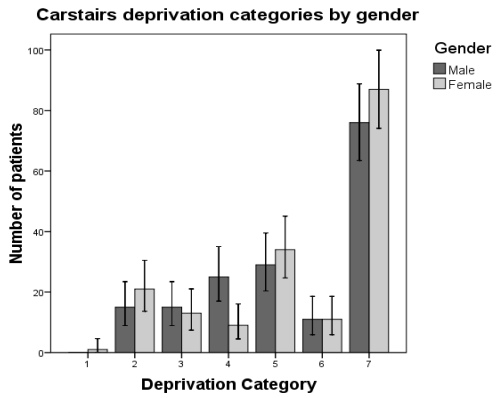


Figure 10: Carstairs deprivation categories compared by gender with 95% confidence intervals.

Overall, 247 (69.9%) patients completed Q1 within six months of their diagnosis. Of these, 170 (48.1%) completed Q1 within six weeks of diagnosis. (This does not include the two Q1's which were completed prior to a diagnosis being confirmed.) There was no overall significant difference in time of Q1 from diagnosis between gender (X^2=5.341, df=5, p=0.376).

6.1.4 Treatments and Time from Diagnosis

Patients attending the lung clinic included newly diagnosed patients and routine return patients. This range of treatment stages represented also included those pre-treatment, those undertaking curative intent treatments (surgery and radical radiotherapy), those undertaking palliative treatments and those receiving supportive care. These have been tabulated (Table 22). To account for the effect of 'routine returns' increasing any

particular form of treatment, groupings of 'time of POS from diagnosis' was used to further evaluate treatments delivered (Table 23).

Treatments delivered tabulated by year groups and gender						
	Male		**Female**		**Total**	
All years combined, n=353	Number	%	Number	%	Number	%
Treatment Given	163	50.6%	159	49.4%	322	100.0%
Surgery	32	9.9%	30	9.3%	62	19.3%
Radical Radiotherapy	13	4.0%	13	4.0%	26	8.1%
Palliative Radiotherapy	51	15.8%	44	13.7%	95	29.5%
Chemotherapy	34	10.6%	47	14.6%	81	25.2%
Supportive Care	25	7.8%	24	7.5%	49	15.2%
Combined	8	2.5%	1	0.3%	9	2.8%
Missing	11		20		31	
Year 1, n=177	Number	%	Number	%	Number	%
Treatment Given	81		85		166	100.0%
Surgery	22	13.3%	18	10.8%	40	24.1%
Radical Radiotherapy	4	2.4%	7	4.2%	11	6.6%
Palliative Radiotherapy	25	15.1%	18	10.8%	43	25.9%
Chemotherapy	16	9.6%	28	16.9%	44	26.5%
Supportive Care	11	6.6%	13	7.8%	24	14.5%
Combined	3	1.8%	1	0.6%	4	2.4%
Missing	7		4		11	
Years 2 & 3, n=176	Number	%	Number	%	Number	%
Treatment Given	82		74		156	100.0%
Surgery	10	6.4%	12	7.7%	22	14.1%
Radical Radiotherapy	9	5.8%	6	3.8%	15	9.6%
Palliative Radiotherapy	26	16.7%	26	16.7%	52	33.3%
Chemotherapy	18	11.5%	19	12.2%	37	23.7%
Supportive Care	14	9.0%	11	7.1%	25	16.0%
Combined	5	3.2%	0	0.0%	5	3.2%
Missing	4		16		20	

Table 22: Table of treatments by gender: number and percentage of known treatments within all years and the in year 1 and years 2/3.

There was a significant difference across the year groups of time from diagnosis to Q1 (X^2=48.55, df=5, p<0.01).

Treatments delivered by time of Q1 from diagnosis, year groups and gender						
	Male		Female		Total	
Q1 within 6 weeks of diagnosis						
All years combined, n=170	Number	%	Number	%	Number	%
Treatment Given	77	52.0%	71	48.0%	148	100.0%
Surgery	5	3.4%	5	3.4%	10	6.8%
Radical Radiotherapy	5	3.4%	5	3.4%	10	6.8%
Palliative Radiotherapy	28	18.9%	30	20.3%	58	39.2%
Chemotherapy	20	13.5%	20	13.5%	40	27.0%
Supportive Care	16	10.8%	11	7.4%	27	18.2%
Combined	3	2.0%	0	0.0%	3	2.0%
Missing	7	4.7%	15	10.1%	22	14.9%
Year 1						
Treatment Given	31	54.4%	26	45.6%	57	100.0%
Surgery	1	1.8%	3	5.3%	4	7.0%
Radical Radiotherapy	0	0.0%	1	1.8%	1	1.8%
Palliative Radiotherapy	16	28.1%	11	19.3%	27	47.4%
Chemotherapy	8	14.0%	8	14.0%	16	28.1%
Supportive Care	6	10.5%	3	5.3%	9	15.8%
Combined	0	0.0%	0	0.0%	0	0.0%
Missing	5	8.8%	2	3.5%	7	12.3%
Years 2 & 3						
Treatment Given	45	43.7%	58	56.3%	103	100.0%
Missing	2	1.9%	13	12.6%	15	14.6%
Surgery	4	3.9%	2	1.9%	6	5.8%
Radical Radiotherapy	5	4.9%	4	3.9%	9	8.7%
Palliative Radiotherapy	12	11.7%	19	18.4%	31	30.1%
Chemotherapy	12	11.7%	12	11.7%	24	23.3%
Supportive Care	10	9.7%	8	7.8%	18	17.5%
Combined	3	2.9%	0	0.0%	3	2.9%
Q1 within 3 months of diagnosis						
All years combined, n=204	Number	%	Number	%	Number	%
Treatment Given	95	52.8%	85	47.2%	180	100.0%
Surgery	7	3.9%	7	3.9%	14	7.8%
Radical Radiotherapy	7	3.9%	6	3.3%	13	7.2%
Palliative Radiotherapy	37	20.6%	35	19.4%	72	40.0%
Chemotherapy	21	11.7%	24	13.3%	45	25.0%
Supportive Care	19	10.6%	13	7.2%	32	17.8%
Combined	4	2.2%	0	0.0%	4	2.2%
Missing	8	4.4%	16	8.9%	24	13.3%
Year 1						
Treatment Given	35	52.2%	32	47.8%	67	100.0%
Surgery	1	1.5%	3	4.5%	4	6.0%
Radical Radiotherapy	0	0.0%	1	1.5%	1	1.5%
Palliative Radiotherapy	19	28.4%	14	20.9%	33	49.3%
Chemotherapy	8	11.9%	10	14.9%	18	26.9%
Supportive Care	6	9.0%	4	6.0%	10	14.9%
Combined	1	1.5%	0	0.0%	1	1.5%
Missing	6	9.0%	2	3.0%	8	11.9%
Years 2 & 3						
Treatment Given	60	53.1%	53	46.9%	113	100.0%
Surgery	6	5.3%	4	3.5%	10	8.8%
Radical Radiotherapy	7	6.2%	5	4.4%	12	10.6%
Palliative Radiotherapy	18	15.9%	21	18.6%	39	34.5%
Chemotherapy	13	11.5%	14	12.4%	27	23.9%
Supportive Care	13	11.5%	9	8.0%	22	19.5%
Combined	3	2.7%	0	0.0%	3	2.7%
Missing	2	1.8%	14	12.4%	16	14.2%
Q1 within 6 months of diagnosis						
All years combined, n=247	Number	%	Number	%	Number	%
Treatment Given	116	52.7%	104	47.3%	220	100.0%
Surgery	8	3.6%	11	5.0%	19	8.6%
Radical Radiotherapy	9	4.1%	6	2.7%	15	6.8%
Palliative Radiotherapy	45	20.5%	38	17.3%	83	37.7%
Chemotherapy	29	13.2%	33	15.0%	62	28.2%
Supportive Care	21	9.5%	16	7.3%	37	16.8%
Combined	4	1.8%	0	0.0%	4	1.8%
Missing	9	4.1%	18	8.2%	27	12.3%
Year 1						
Treatment Given	44	50.0%	44	50.0%	88	100.0%
Surgery	2	2.3%	5	5.7%	7	8.0%
Radical Radiotherapy	1	1.1%	1	1.1%	2	2.3%
Palliative Radiotherapy	22	25.0%	14	15.9%	36	40.9%
Chemotherapy	11	12.5%	17	19.3%	28	31.8%
Supportive Care	7	8.0%	7	8.0%	14	15.9%
Combined	1	1.1%	0	0.0%	1	1.1%
Missing	6	6.8%	3	3.4%	9	10.2%
Years 2 & 3						
Treatment Given	72	54.5%	60	45.5%	132	100.0%
Surgery	6	4.5%	6	4.5%	12	9.1%
Radical Radiotherapy	8	6.1%	5	3.8%	13	9.8%
Palliative Radiotherapy	23	17.4%	24	18.2%	47	35.6%
Chemotherapy	18	13.6%	16	12.1%	34	25.8%
Supportive Care	14	10.6%	9	6.8%	23	17.4%
Combined	3	2.3%	0	0.0%	3	2.3%
Missing	3	2.3%	15	11.4%	18	13.6%

Table 23: Treatments by gender in those with first questionnaire completed within six weeks, three months and six months from diagnosis in all years and year 1 and years 2/3.

6.1.5 Discussion

The population attending the lung multidisciplinary clinic in Stobhill is in keeping with lung cancer populations reported within the literature and in comparison to the national lung cancer audit (Table 24).

Chracteristic	Stobhill lung cancer service	Data sourced from national lung cancer audit
Gender		
Male	49.30%	53%
Female	50.70%	47%
Age		
50 years and less	2.80%	6.15%
51-69	46.50%	35.31%
70 years and more	50.70%	58.54%
Histology		
NSCLC	68%	60.90%
SCLC	13%	15%
No/Negative histology	19%	19.80%
Other	na	2.80%
Stage		
1a	0.80%	3.31%
1b	5.80%	3.94%
2a	5.00%	0.55%
2b	1.70%	2.29%
3a	5.00%	4.42%
3b	25.60%	8.18%
4	38.00%	22.99%
Treatment		
Surgery	19.3%*	9.88%
Chemotherapy	25.20%	25.24%
Radiotherapy	37.60%	22.04%
Palliative Care	15.20%	17.61%
Active monitoring	na	12.86%
Performance status		
0	14.40%	13.19%
1	34.30%	21.24%
2	19.30%	13.66%
3	22.90%	11.17%
4	3.40%	3.72%
5	na	16.76%
Missing	5.70%	20.27%
		*Note discussion

Table 24: Comparison of evaluation sample population characteristics to national audit.

The patients tended to be over 65 years old, with half over the age of 70 years. Gregor et al[41] reported a similar age spread in 1995 from a Scottish lung cancer population (median 70 years, range 34-97).

Histological types are represented in expected proportions with around 70% of patients having NSCLC and 13% known to be SCLC. The 19% of patients with a clinico-radiological diagnosis is also in keeping with the literature. In 1995 Gregor et al[41] reported 23.7% SCLC, 58.2% NSCLC and 18% unknown or other. The recent national lung cancer audit reported histological rates in Scotland as 60.9% NSCLC, 15% SCLC and 19.8% without histology.[3]

Advanced disease is common in each cell type. It is of note that out of the 353 patients, 185 (52.4%) had advanced incurable disease (> stage 3A or extensive SCLC). The national lung cancer audit reports 40.9% of patients with advanced incurable disease in England and Wales.[3] Furthermore, one third of patients attending the clinic had metastatic disease. This is in keeping with the 31.2% of metastatic disease at presentation reported in 1995[41] and the 29.8% in England and Wales reported in the national lung cancer audit.[3]

It is of note that there were slightly more females (50.7%) than males (49.3%). This is less usual in lung cancer care and within the literature. Gregor et al[41] reported 60.7% of the study population were male in 1995, and this is similar to the 59% males reported in England and Wales in 2007.[3] Other studies have reported smaller differences between proportions of genders.[164, 286] Furthermore, the clinic at Stobhill has seen an increase in referrals of females. This has been found within both in-house audits and as part of other studies within the same time period as this study.[189, 190] This may reflect the increase within Scotland of lung cancer in the female population.[36] Between 1995 and 2005 there has been a 23.7% decrease in age-standardised incidence in lung cancer in men and a 3.5% increase in females.[36]

There is a bias in year one with more completing Q1 as returning patients rather than newly diagnosed patients. This is to be expected as the LCQ is completed for the first time by any patient in year one. After the first year, most of the returning patients would have already completed a Q1 or would be deceased and therefore more newly diagnosed patients predominate in years 2/3. As such, the overall treatment rates and patient representation will be biased towards survivors returning to the clinic within the first year. This bias was accounted for by sub-group analysis.

Overall survival of this lung cancer population was 11.47 months when evaluating all patients who returned a single questionnaire. This median survival is higher than the expected due to the bias towards including survivors in the sample. When considering overall survival in newly diagnosed patients only, the median was 9.13 months. Median survival from lung cancer in Scotland has been reported as 3.6 months,[41, 42] 5.2 months,[43] 6 months,[44] and 9.1 months[45] dependent on area of Scotland and patient selection. It is likely there is some participation bias towards longer survivors in this study.

The majority of patients presenting with lung cancer have disease not amenable to surgical resection.[41] In this study 19.3% of *all patients* completing a questionnaire had undergone surgery (24.1% of year one population and 14.1% years 2/3 population; see Table 22). However, when considering newly diagnosed patients only (excluding routine returns), 6.8% of patients underwent surgery (Table 23). This is in keeping with the national audit proportions of patients undergoing surgical resection: 9.26% in England and Wales and 9.7% in Scotland.[3]

In newly diagnosed patients, 6.8% underwent radical radiotherapy and a further 39.2% received palliative radiotherapy (Table 23). Overall, 18.2% of patients undertook curative intent treatments (surgical resection, radical radiotherapy and chemotherapy in limited stage SCLC). In 2007, 62.3% of newly diagnosed lung cancer patients in Scotland received active anti-cancer treatments (including curative and non-curative intent treatments).[3] In this study, around 79% of newly diagnosed patients received anti-cancer treatment, with the palliative radiotherapy being delivered in 39.2% of patients (Table 23).

In keeping with the out-patient study setting, most patients have a performance status doctor-rated at diagnosis as 2 or less (84.4%). The national lung cancer audit found 48.09% of patients had a PS of 2 or less.[3] However, 20.2% of patients had no recorded PS in the national audit and in-patients were also audited.

The deprivation within the lung cancer population at this clinic is high. This is in keeping with expectation as the Stobhill Hospital catchment area covers several deprived areas within North Glasgow. Furthermore, deprivation has been found to be an independent risk factor for developing lung cancer in several countries,[333-335] including Scotland.[52] Survival from diagnosed lung cancer may also be reduced in those with higher deprivation, even within the population undergoing curative intent surgery.[336] There is also some evidence that a lower baseline quality of life in lung cancer is associated with deprivation.[53] This is of particular note for this study which evaluates supportive care needs within a population with short survival rates. This study provides a focused view of a largely deprived population in which supportive care needs may require rapid identification to allow sufficient and timely care provision to meet those needs.

6.1.6 Conclusions

Patients included in this analysis are in keeping with the expected range of histology and stages of lung cancer in an out-patient clinic. There are more females in this population than previously published articles, but this may reflect the changing trends within lung cancer incidence in Scotland and reflects the current situation in Stobhill. Median survival in this population is high compared to previously published studies. It is likely there is some participation bias towards survivors in this study. Other demographic variables are in keeping with published literature. When considering newly diagnosed patients, curative intent treatments were undertaken in 18.2% of patients. There is a high level of deprivation within this patient group and this may be associated with increased supportive care needs and shortened survival. This will be evaluated in subsequent sections.

6.2 Descriptive Analysis of LCQ Responses

In keeping with the primary aim of this study (Section 2), the prevalence of supportive care needs within Stobhill Hospital's lung cancer multidisciplinary clinic and overall supportive care needs are considered in three groupings:

1. All patients attending the lung cancer clinic population (all first questionnaires returned (Q1)). *Filter: Q1 selected from Q1 or not Q1*.
2. Patients with newly diagnosed lung cancer (Q1 < six weeks post-diagnosis). *Filter: as above AND additional criteria Q1 < six weeks from diagnosis.*
3. Those within three months of death from any cause. Filter: vital status=dead AND QF selected AND death within three months of QF.

In keeping with Aims 1, 4 and 5 (Section 2), responses to the additional questions are presented in the same three groupings.

As described in Section 3 both descriptive statistics of centrality are given to allow comparison with other published symptom assessment data and results have been further evaluated in terms of three categories: 'none or mild', 'moderate' and 'severe to overwhelming', and 95% confidence intervals for POS scores were calculated.

6.2.1 All patients Attending the Lung Cancer Clinic

6.2.1.1 Responses to POS Questions

Overall, 303 (85.8%) patients completed all the POS questions, thus allowing a summary score out of 40 to be calculated (n=353). Fifty (14.2%) patients did not fully complete the POS questions but some have responded to a proportion of individual questions. Summary statistics are tabulated below (Table 25).

	N	Percentage	Mean	Standard Deviation	95% CI of mean	Median	Range
Palliative outcome scale summary score	303	85.8%	9.81	5.87	0.66	9	0-27
Pain	341	96.6%	1.28	1.18	0.13	1	0-4
Other symptoms	332	94.1%	0.65	0.97	1.04	0	0-4
Personal anxiety	334	94.6%	1.63	1.31	0.14	1	0-4
Perceived anxiety within support network	332	94.1%	2.17	1.40	0.15	2	0-4
Ability to share	332	94.1%	0.75	1.19	0.13	0	0-4
Life-worth	320	90.7%	0.55	0.90	0.10	0	0-4
Self-worth	325	92.1%	1.26	1.20	0.13	1	0-4
Information	309	87.5%	0.72	1.19	0.13	0	0-4
Practical issues	315	89.2%	0.52	0.88	0.10	0	0-3
Time use	321	90.9%	0.14	0.45	0.05	0	0-2
Form completion	331	93.8%	0.53	0.53	0.06	1	0-2

Table 25: Summary statistics of overall and individual POS scores.

POS individual question responses and summary scores alongside patient-rated PS are displayed in Figure 11. Individual bar charts of responses to each question with 95% CI are displayed in Appendix 5 (Figure 21A and B). A table showing patient responses categorised into none-mild, moderate and severe-overwhelming is displayed (Table 26).

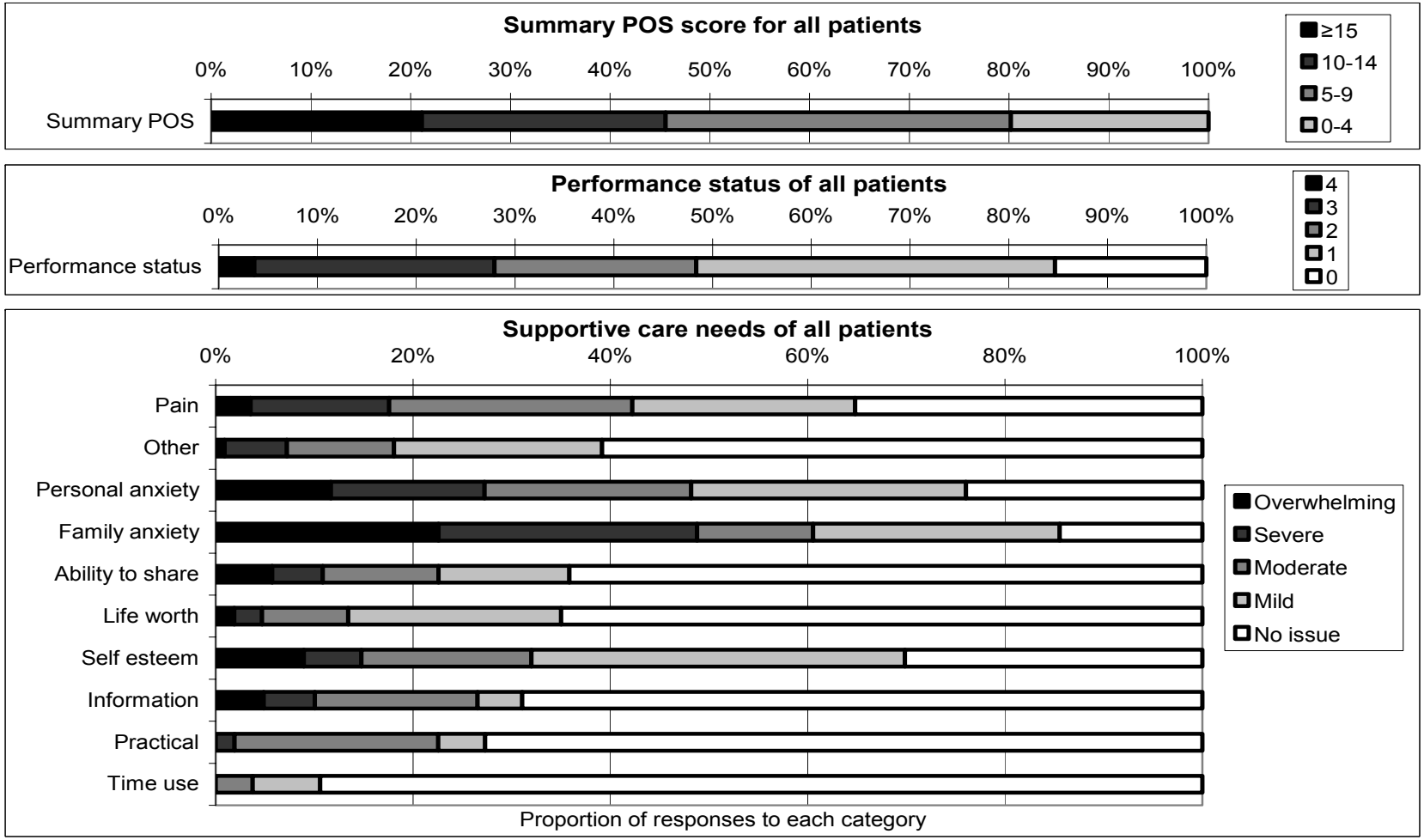


Figure 11: Stacked bar charts showing POS scores, PS and responses to POS questions for all patients. Percentages adjusted to account for missing data.

Analysis of Palliative Outcome Scale from First Questionnaire (Q1)						
	Male		Female		Total	
	Number	%	Number	%	Number	%
Questionnaires						
Number of lung cancer clinic questionnaires completed	174	49.3%	179	50.7%	353	100.0%
Number of fully completed POS questions	148	41.9%	155	43.9%	303	85.8%
Incomplete POS questions	26	7.4%	24	9.4%	50	14.2%
Summary POS score	148	41.9%	155	43.9%	303	85.8%
0-4	36	10.2%	24	6.8%	60	17.0%
5-9	51	14.4%	54	15.3%	105	29.7%
10-15	35	9.9%	39	11.0%	74	21.0%
≥15	26	7.4%	38	10.8%	64	18.1%
Missing	26	7.4%	24	6.8%	50	14.2%
Have you been affected by pain?	167	47.3%	174	49.3%	341	96.6%
None or slight	93	26.3%	104	29.5%	197	55.8%
Moderately	42	11.9%	42	11.9%	84	23.8%
Severe or overwhelming	32	9.1%	28	7.9%	60	17.0%
Missing	7	2.0%	5	1.4%	12	3.4%
Have any other symptoms been affecting how you feel?	161	45.6%	171	48.4%	332	94.1%
None or slight	130	36.8%	142	40.2%	272	77.1%
Moderately	20	5.7%	16	4.5%	36	10.2%
Severe or overwhelming	11	3.1%	13	3.7%	24	6.8%
Missing	13	3.7%	8	2.3%	21	5.9%
Have you felt anxious or worried about your illness or treatment?	162	45.9%	172	48.7%	334	94.6%
None or slight	92	26.1%	81	22.9%	173	49.0%
Moderate	34	9.6%	36	10.2%	70	19.8%
High anixiety (severe-overwhelming)	36	10.2%	55	15.6%	91	25.8%
Missing	12	3.4%	7	2.0%	19	5.4%
Have any of your friends or family about your illness or treatment?	162	45.9%	170	48.2%	332	94.1%
None or slight	68	19.3%	63	17.8%	131	37.1%
Moderate	12	3.4%	27	7.6%	39	11.0%
High anixiety (severe-overwhelming)	82	23.2%	80	22.7%	162	45.9%
Missing	12	3.4%	9	2.5%	21	5.9%
Have you been able to share how you are feeling with family or friends?	161	45.6%	171	48.4%	332	94.1%
Most or as much as wanted	130	36.8%	127	36.0%	257	72.8%
Sometimes	12	3.4%	27	7.6%	39	11.0%
Ocassionnally or not at all	19	5.4%	17	4.8%	36	10.2%
Missing	13	3.7%	8	2.3%	21	5.9%
Have you felt life was worthwhile?	154	43.6%	166	47.0%	320	90.7%
Yes to most of time	140	39.7%	137	38.8%	277	78.5%
Sometimes	8	2.3%	20	5.7%	28	7.9%
Occasionnally or not at all	6	1.7%	9	2.5%	15	4.2%
Missing	20	5.7%	13	3.7%	33	9.3%
Have you felt good about yourself?	158	44.8%	167	47.3%	325	92.1%
Yes to most of time	120	34.0%	101	28.6%	221	62.6%
Sometimes	21	5.9%	35	9.9%	56	15.9%
Occasionnally or not at all	17	4.8%	31	8.8%	48	13.6%
Missing	16	4.5%	12	3.4%	28	7.9%
How much information has been given?	152	43.1%	157	44.5%	309	87.5%
Full info to full info but some hard to understand	118	33.4%	109	30.9%	227	64.3%
Info on request but wanted more	24	6.8%	27	7.6%	51	14.4%
Very little to no information	10	2.8%	21	5.9%	31	8.8%
Missing	22	6.2%	22	6.2%	44	12.5%
Have practical matters, relating to your illness, been addressed?	153	43.3%	162	45.9%	315	89.2%
No issues or issues addressed	113	32.0%	131	37.1%	244	69.1%
Practical issues are currently being addressed	37	10.5%	28	7.9%	65	18.4%
Practical issues exist which have not been addressed	3	0.8%	3	0.8%	6	1.7%
Missing	21	5.9%	17	4.8%	38	10.8%
How much time do you feel has been wasted through healthcare?	158	44.8%	163	46.2%	321	90.9%
None at all	145	41.1%	142	40.2%	287	81.3%
Up to half a day wasted	10	2.8%	12	3.4%	22	6.2%
More than half a day wasted	3	0.8%	9	2.5%	12	3.4%
Unknown	16	4.5%	16	4.5%	32	9.1%
Form Completion	161	45.6%	170	48.2%	331	93.8%
Self	89	25.2%	71	20.1%	160	45.3%
Help from family	68	19.3%	97	27.5%	165	46.7%
Help from Staff	4	1.1%	2	0.6%	6	1.7%
Unknown	13	3.7%	9	2.5%	22	6.2%

Table 26: Responses to POS (summary score and individual questions) in categories compared across genders (n=353). Missing data presented.

In this analysis of all patients attending a lung cancer clinic, most respondents were able to complete the questionnaire by themselves (45.3%) or with help from family or friends (46.7%). Very few patients required help from staff to compete the form (1.7%).

At least one supportive care need was recorded for 295 (97.4%) patients completing a full POS score (n=303). The overall mean POS score was 9.81 (SD 5.87, 95% CI 9.15-10.47) and the median was 9. As such, when grouping patients into 'higher' or 'lower' supportive care needs, a cut off of ≥10 is used.

Six out of ten of the issues assessed by POS had a median value of 0, and three issues (pain, personal anxiety and self-worth) had median values of 1. The only issue identified by POS with a median value rated moderate or above was 'perceived anxiety within the patient's support network' ($\bar{x}$ = 2.17, SD 1.40, median 2).

Prevalences of moderate to overwhelming issues were as follows: 201 patients (56.9%, 95% CI 51.7-62%) felt their support network was anxious, 161 (45.6%, 95% CI 40.5-50.8%) reported personal anxiety, 144 (40.8%, 95% CI 35.8-46.0%) pain, 108 (30.5%, 95% CI 26-35.6%) had information needs, 104 (29.6%, 95% CI 24.9-34.4%) reduced self-esteem, 75 (21.2%, 95% CI 17.3 – 25.8%) a low ability to share, 71 (20.1%, 95% CI 16.3-24.6%) reported unmet practical needs, 60 (17%, 95% CI 13.4-21.3%) affected by 'other' symptoms, 43 (12.1%, 95% CI 9.2-16%) felt life was worthwhile only sometimes to not at all and only 33 (9.6%, 95% CI 6.7%-12.8%) reported half or more of a day had been wasted through health care appointments.

6.2.1.2 Responses to Respiratory Symptoms, Service Views and Other Questions

All the respiratory symptom questions were completed by 334 (94.6%) patients out of 353. Ten (2.8%) patients did not fully complete the respiratory questions but some have responded to a proportion of individual questions. A satisfaction score was completed by 131 (37.1%) patients. The questions relating to satisfaction were not included within the first 12 months and, therefore, 177 (50.1%) patients were not able to complete a satisfaction score in Q1. Thus, the 131 completed scores represent 74.4% of the number of possible scores (n=176). Forty-five (25.6%) patients did not fully complete the satisfaction questions but some have responded to a proportion of individual questions.

Summary statistics for respiratory symptom questions and service questions were tabulated (Table 27).

	N	Percentage	Mean	Standard Deviation	95% CI of mean	Median	Range
Overview of all patients attending clinic n=353							
Respiratory symptom summary score	334	94.6%	3.00	1.91	0.20	3	0-10
Dypsnoea	342	96.9%	1.55	1.06	0.11	2	0-4
Cough	338	95.8%	1.23	0.98	0.10	1	0-4
Haemoptysis	334	94.6%	0.23	0.63	0.07	0	0-3
Overview of all patients attending clinic n=353							
Satisfaction score	131	37.1%	1.27	1.49	0.25	1	0-7
Satisfaction with investigations	140	39.7%	0.47	0.68	0.11	0	0-3
Satisfaction with way diagnosis was given	139	39.4%	0.51	0.66	0.11	0	0-3
Satisfaction with follow-up	136	38.5%	0.36	0.54	0.09	0	0-2

Table 27: Summary statistics of overall and individual respiratory and satisfaction scores for all Q1.

Individual bar charts with 95% CI for all non-POS item responses for all patients' Q1 are displayed in Figure 12A and B. A table showing symptom responses categorised into none-mild, moderate and severe-overwhelming and also service question responses is displayed (Table 28).

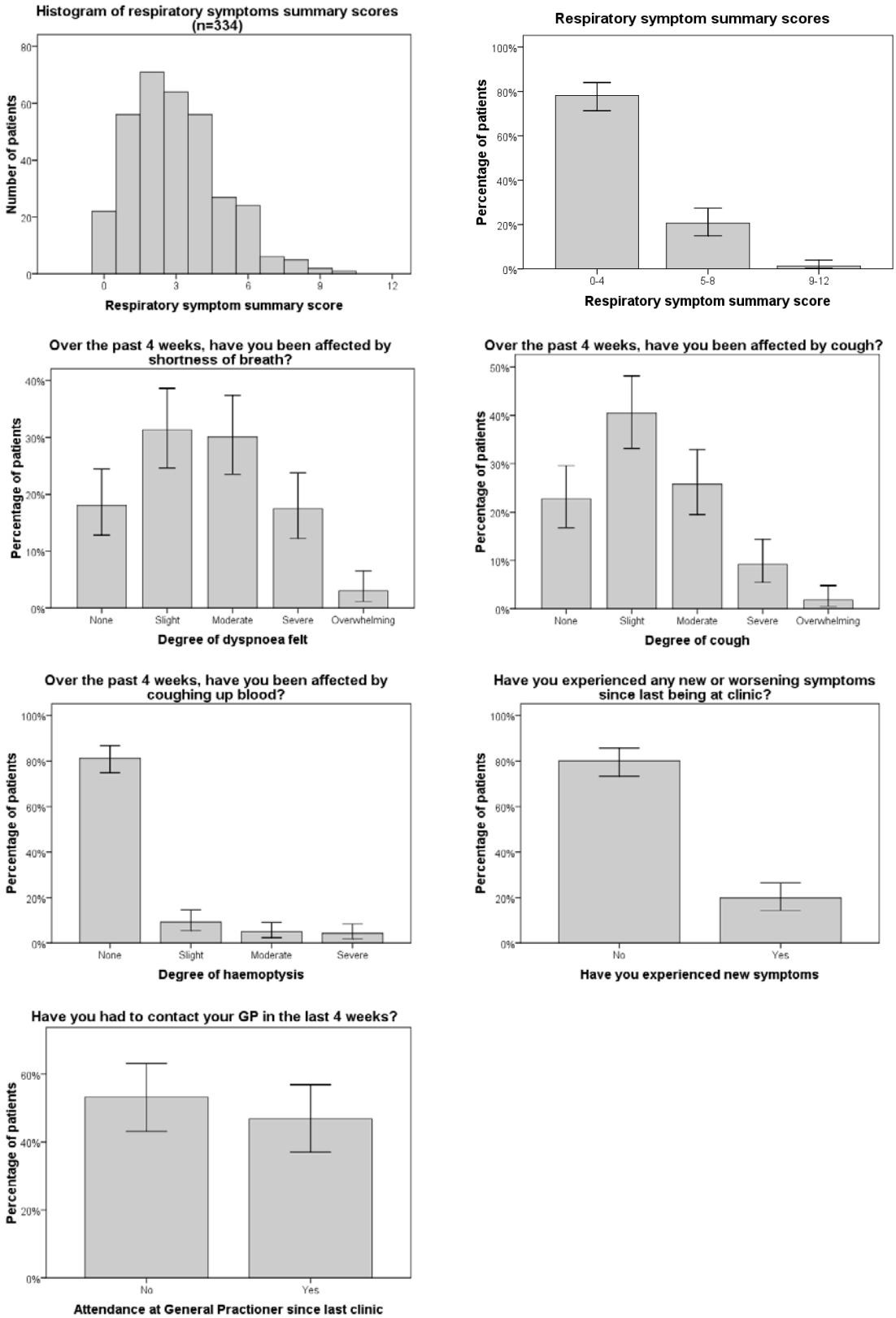


Figure 12A: Histogram and bar charts of patient responses to respiratory symptom and other symptom-related questions (Q1). Percentages adjusted for missing data and 95% CI included.

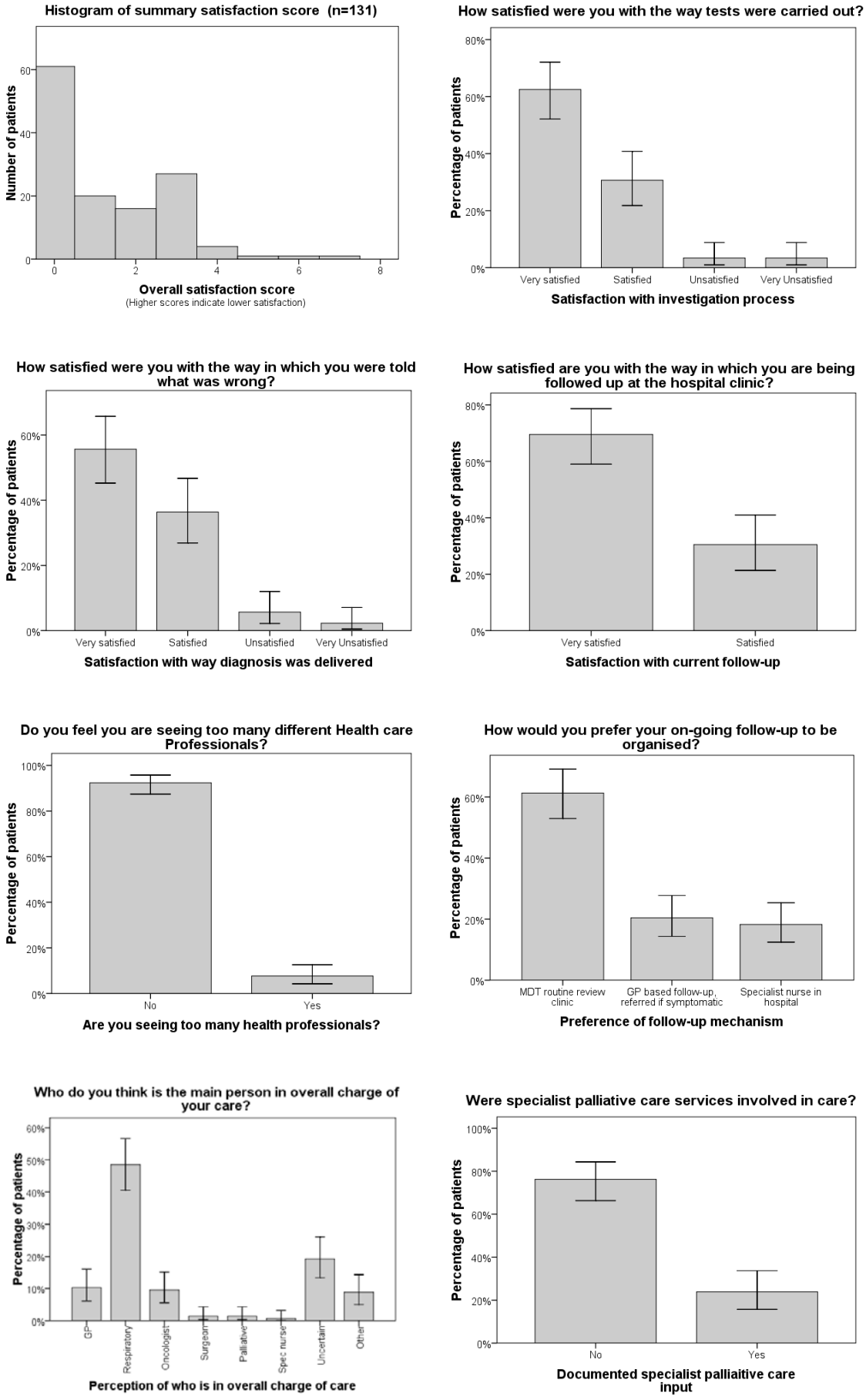


Figure 12B: Histogram and bar charts of patient responses to service questions (Q1). Percentages adjusted for missing data and 95% CI included.

Analysis of Respiratory and other symptom questions from Q1 across gender						
	Male		Female		Total	
	Number	%	Number	%	Number	%
Questionnaires						
Number of lung clinic questionnaires completed	174	49.3%	179	50.7%	353	100.0%
Number of fully completed respiratory questions	164	46.5%	170	48.2%	334	94.6%
Incomplete respiratory questions	10	2.8%	9	2.5%	19	5.4%
Summary Respiratotry Score	164	46.5%	170	48.2%	334	94.6%
0-4	132	37.4%	137	38.8%	269	76.2%
5-8	30	8.5%	32	9.1%	62	17.6%
9-12	2	0.6%	1	0.3%	3	0.8%
Missing	10	2.8%	9	2.5%	19	5.4%
Have you been affected by dyspnoea?	167	47.3%	175	49.6%	342	96.9%
None or slight	84	23.8%	82	23.2%	166	47.0%
Moderate	56	15.9%	56	15.9%	112	31.7%
Severe or overwhelming	27	7.6%	37	10.5%	64	18.1%
Missing	7	2.0%	4	1.1%	11	3.1%
Have you been affected by cough?	166	47.0%	172	48.7%	338	95.8%
None or slight	102	28.9%	114	32.3%	216	61.2%
Moderate	46	13.0%	43	12.2%	89	25.2%
Severe or overwhelming	18	5.1%	15	4.2%	33	9.3%
Missing	8	2.3%	7	2.0%	15	4.2%
Have you been affected by haemoptysis?	163	46.2%	171	48.4%	334	94.6%
None or slight	151	42.8%	163	46.2%	314	89.0%
Moderate	8	2.3%	4	1.1%	12	3.4%
Severe or overwhelming	4	1.1%	4	1.1%	8	2.3%
Missing	11	3.1%	8	2.3%	19	5.4%
Have you had any new or worsening symptoms since last clinic?	166	47.0%	173	49.0%	339	96.0%
No	122	34.6%	127	36.0%	249	70.5%
Yes	44	12.5%	46	13.0%	90	25.5%
Missing	8	2.3%	6	1.7%	14	4.0%
Have you had to contact your GP since last clinic?	74	21.0%	77	21.8%	151	42.8%
No	32	9.1%	44	12.5%	76	21.5%
Yes	42	11.9%	33	9.3%	75	21.2%
Missing	100	28.3%	102	28.9%	202	57.2%
Satisfaction summary Score	66	18.7%	65	18.4%	131	37.1%
0-4	65	18.4%	63	17.8%	128	36.3%
5-8	1	0.3%	2	0.6%	3	0.8%
9-12	0	0.0%	0	0.0%	0	0.0%
Missing	108	30.6%	114	32.3%	222	62.9%
How satisfied were you with the way tests were carried out?	68	19.3%	72	20.4%	140	39.7%
Very satisfied or satisfied	65	18.4%	68	19.3%	133	37.7%
Unsatisfied or very unsatisfied	3	0.8%	4	1.1%	7	2.0%
Missing	106	30.0%	107	30.3%	213	60.3%
How satisfied were you with the way your diagnosis was given?	68	19.3%	71	20.1%	139	39.4%
Very satisfied or satisfied	66	18.7%	64	18.1%	130	36.8%
Unsatisfied or very unsatisfied	2	0.6%	7	2.0%	9	2.5%
Missing	106	30.0%	108	30.6%	214	60.6%
How satisfied were you with the way you are being followed-up?	68	19.3%	68	19.3%	136	38.5%
Very satisfied or satisfied	67	19.0%	65	18.4%	132	37.4%
Unsatisfied or very unsatisfied	1	0.3%	3	0.8%	4	1.1%
Missing	106	30.0%	111	31.4%	217	61.5%
Do you feel you are seeing to many health care professionals	158	44.8%	164	46.5%	322	91.2%
No	148	41.9%	149	42.2%	297	84.1%
Yes	10	2.8%	15	4.2%	25	7.1%
Missing	16	4.5%	15	4.2%	31	8.8%
How would you prefer to be followed-up?	137	38.8%	141	39.9%	278	78.8%
MDT clinic with routine review	87	24.6%	92	26.1%	179	50.7%
GP based system, referred back if symptoms occur	36	10.2%	29	8.2%	65	18.4%
Hospital-based specialist nurse	14	4.0%	20	5.7%	34	9.6%
Missing	37	10.5%	38	10.8%	75	21.2%
Who do you think is in over all charge of your care?	145	41.1%	160	45.3%	305	86.4%
GP	29	8.2%	32	9.1%	61	17.3%
Respiratory Consultant	79	22.4%	74	21.0%	153	43.3%
Oncologist	11	3.1%	18	5.1%	29	8.2%
Surgeon	1	0.3%	3	0.8%	4	1.1%
Palliative Care Consultant	2	0.6%	0	0.0%	2	0.6%
Specialist nurse	2	0.6%	2	0.6%	4	1.1%
Uncertain	13	3.7%	19	5.4%	32	9.1%
Other	8	2.3%	12	3.4%	20	5.7%
Missing	29	8.2%	19	5.4%	48	13.6%
Has palliative care been involved in care?	77	21.8%	77	21.8%	154	43.6%
No	49	13.9%	63	17.8%	112	31.7%
Yes	28	7.9%	14	4.0%	42	11.9%
Missing	97	27.5%	102	28.9%	199	56.4%

Table 28: Responses to respiratory and other symptom questions (summary score and individual questions) and service-related qeustions compared across gender from Q1. Note: satisfaction questions were not available in year 1. Missing data presented.

At least one respiratory symptom was reported for 312 (93.4%, n=334) patients completing a respiratory score. The only respiratory symptom identified as moderate or above was dyspnoea (median 2). Prevalence of moderate to overwhelming symptoms were as follows: dyspnoea 176 (49.8%, 95% CI 44.7-55.0%), cough 122 (34.5%, 95% CI 29.8-39.7%) and haemoptysis 20 (5.7%, 95% CI 3.7-8.6%).

When satisfaction was assessed, the majority of patients were either very satisfied or satisfied with the investigation process (133; 75.6%), diagnosis disclosure (130; 73.9%) and follow-up (132; 80%).

The majority (70.5%) of patients indicated no new or changing symptoms and 21.2% had contacted their GP since their last clinic review. Most (84.1%) did not feel they were seeing too many health care professionals and slightly more than half of patients (50.7%) preferred follow-up at the MDT clinic with routine review. However, 18.4% of patients would prefer a GP-led follow-up system and 9.6% a nurse-led follow-up; 21.2% did not express an opinion. One hundred and twelve (72.7%, n=154) patients did not have documented palliative care input (this was only reviewed in year 2/3). Most (43.3%) patients identified the respiratory consultant as in charge of care, 17.3% GP, 8.2% oncologist and 2.8% surgeon, palliative care or specialist nurse. Some (14.8%) were uncertain or suggested ‘other’, and 13.6% did not reply.

6.2.2 Newly Diagnosed Patients

6.2.2.1 Responses to POS Questions

For 170 patients out of 353 (48.2%), Q1 was completed within six weeks of diagnosis. One hundred and forty-seven (86.5%) of these patients completed all of the POS questions, thus allowing a summary score out of 40 to be calculated. Twenty-three patients (13.5%) did not fully complete the POS questions but some have responded to a proportion of individual questions. Summary statistics are tabulated below (Table 29).

	N	Percentage	Mean	Standard Deviation	95% CI of mean	Median	Range
Palliative Outcome Scale summary score	147	86.5%	10.74	5.85	0.95	10	1-27
Pain	166	97.6%	1.33	1.23	0.19	1	0-4
Other symptoms	161	94.7%	0.63	0.97	0.15	0	0-4
Personal anxiety	162	95.3%	1.93	1.35	0.21	2	0-4
Perceived anxiety within support network	161	94.7%	2.63	1.23	0.19	3	0-4
Ability to share	161	94.7%	0.75	1.23	0.19	0	0-4
Life-worth	155	91.2%	0.55	0.94	0.15	0	0-4
Self-worth	158	92.9%	1.28	1.29	0.20	1	0-4
Information	154	90.6%	0.60	0.98	0.15	0	0-3
Practical issues	155	91.2%	0.66	0.98	0.15	0	0-2
Time use	155	91.2%	0.15	0.45	0.07	0	0-2
Form completion	161	94.7%	0.60	0.50	0.08	1	0-2

Table 29: Summary statistics of overall and individual POS scores in recently diagnosed patients (Q1<6 weeks).

POS individual question responses and summary scores alongside patient-rated PS are displayed in Figure 13. Individual bar charts of responses to each question with 95% CI are displayed in Appendix 6 (Figure 22A and B). A table showing responses categorised into none-mild, moderate and severe-overwhelming is displayed (Table 30).

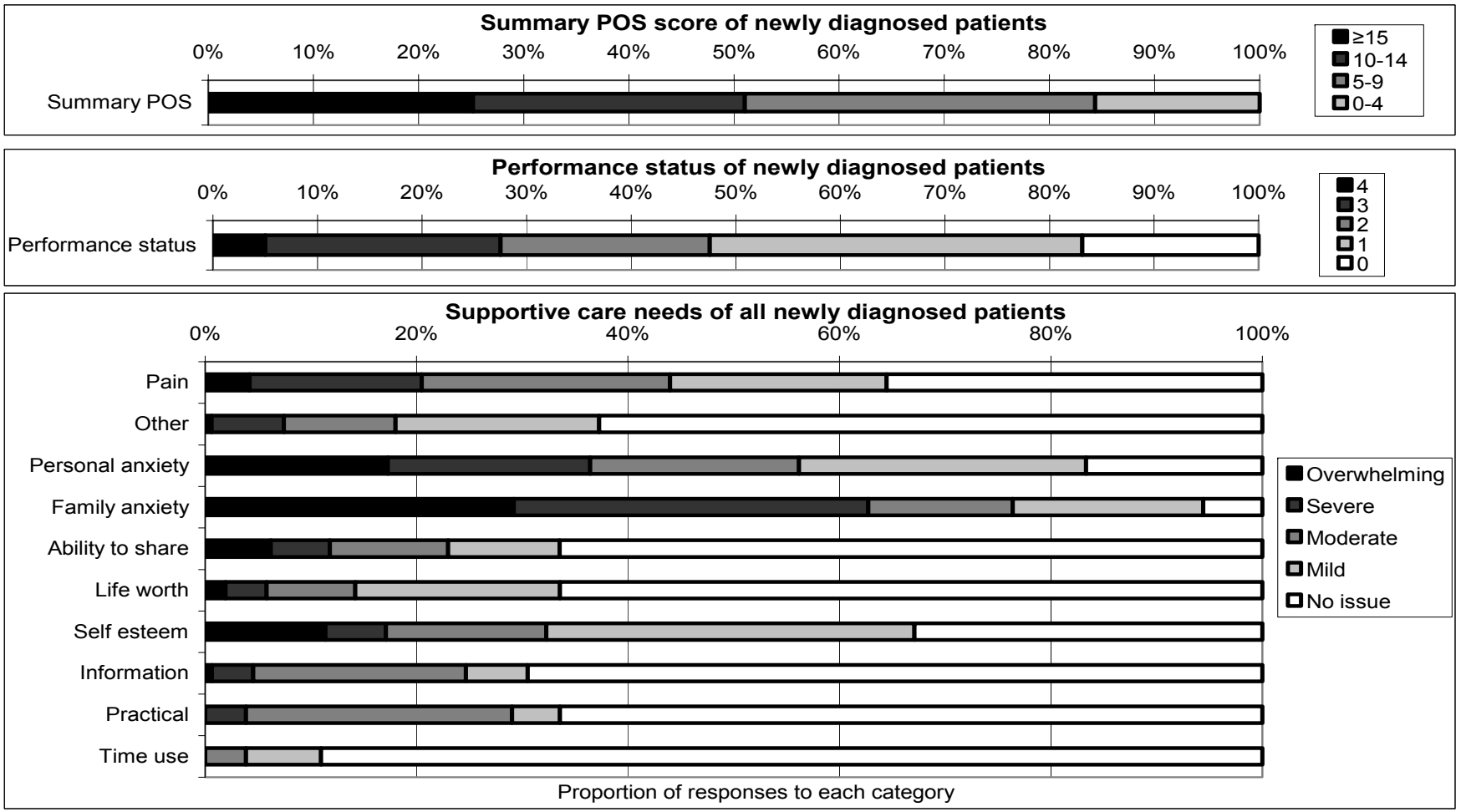


Figure 13: Stacked bar chart showing newly diagnosed patients' POS score, PS and responses to POS question. Percentages adjusted for missing data.

Analysis of Palliative Outcome Scale from First Questionnaire (Q1) in newly diagnosed patients						
	Male		Female		Total	
	Number	%	Number	%	Number	%
Questionnaires						
Number of lung cancer clinic questionnaires completed	84	49.4%	86	50.6%	170	100.0%
Number of fully completed POS questions	72	42.4%	75	44.1%	147	86.5%
Incomplete POS questions	12	7.1%	11	6.5%	23	13.5%
Summary POS score	72	42.4%	75	44.1%	147	86.5%
0-4	13	7.6%	10	5.9%	23	13.5%
5-9	26	15.3%	23	13.5%	49	28.8%
10-15	19	11.2%	19	11.2%	38	22.4%
≥15	14	8.2%	23	13.5%	37	21.8%
Missing	12	7.1%	11	6.5%	23	13.5%
Have you been affected by pain?	82	48.2%	84	49.4%	166	97.6%
None or slight	47	27.6%	46	27.1%	93	54.7%
Moderately	18	10.6%	21	12.4%	39	22.9%
Severe or overwhelming	17	10.0%	17	10.0%	34	20.0%
Missing	2	1.2%	2	1.2%	4	2.4%
Have any other symptoms been affecting how you feel?	79	46.5%	82	48.2%	161	94.7%
None or slight	66	38.8%	66	38.8%	132	77.6%
Moderately	8	4.7%	9	5.3%	17	10.0%
Severe or overwhelming	5	2.9%	7	4.1%	12	7.1%
Missing	5	2.9%	4	2.4%	9	5.3%
Have you felt anxious or worried about your illness or treatment?	80	47.1%	82	48.2%	162	95.3%
None or slight	39	22.9%	32	18.8%	71	41.8%
Moderate	15	8.8%	17	10.0%	32	18.8%
High anixiety (severe-overwhelming)	26	15.3%	33	19.4%	59	34.7%
Missing	4	2.4%	4	2.4%	8	4.7%
Have any of your friends or family about your illness or treatment?	80	47.1%	81	47.6%	161	94.7%
None or slight	21	12.4%	17	10.0%	38	22.4%
Moderate	7	4.1%	15	8.8%	22	12.9%
High anixiety (severe-overwhelming)	52	30.6%	49	28.8%	101	59.4%
Missing	4	2.4%	5	2.9%	9	5.3%
Have you been able to share how you are feeling with family or friends?	79	46.5%	82	48.2%	161	94.7%
Most or as much as wanted	62	36.5%	62	36.5%	124	72.9%
Sometimes	6	3.5%	12	7.1%	18	10.6%
Ocassionnally or not at all	11	6.5%	8	4.7%	19	11.2%
Missing	5	2.9%	4	2.4%	9	5.3%
Have you felt life was worthwhile?	76	44.7%	79	46.5%	155	91.2%
Yes to most of time	69	40.6%	64	37.6%	133	78.2%
Sometimes	4	2.4%	9	5.3%	13	7.6%
Occasionnally or not at all	3	1.8%	6	3.5%	9	5.3%
Missing	8	4.7%	7	4.1%	15	8.8%
Have you felt good about yourself?	78	45.9%	80	47.1%	158	92.9%
Yes to most of time	58	34.1%	49	28.8%	107	62.9%
Sometimes	12	7.1%	12	7.1%	24	14.1%
Occasionnally or not at all	8	4.7%	19	11.2%	27	15.9%
Missing	6	3.5%	6	3.5%	12	7.1%
How much information has been given?	75	44.1%	79	46.5%	154	90.6%
Full info to full info but some hard to understand	56	32.9%	60	35.3%	116	68.2%
Info on request but wanted more	15	8.8%	16	9.4%	31	18.2%
Very little to no information	4	2.4%	3	1.8%	7	4.1%
Missing	9	5.3%	7	4.1%	16	9.4%
Have practical matters, relating to your illness, been addressed?	75	44.1%	80	47.1%	155	91.2%
No issues or issues addressed	49	28.8%	61	35.9%	110	64.7%
Practical issues are currently being addressed	23	13.5%	16	9.4%	39	22.9%
Practical issues exist which have not been addressed	3	1.8%	3	1.8%	6	3.5%
Missing	9	5.3%	6	3.5%	15	8.8%
How much time do you feel has been wasted through healthcare?	76	44.7%	79	46.5%	155	91.2%
None at all	69	40.6%	69	40.6%	138	81.2%
Up to half a day wasted	6	3.5%	5	2.9%	11	6.5%
More than half a day wasted	1	0.6%	5	2.9%	6	3.5%
Unknown	8	4.7%	7	4.1%	15	8.8%
Form Completion	78	45.9%	83	48.8%	161	94.7%
Self	34	20.0%	32	18.8%	66	38.8%
Help from family	43	25.3%	51	30.0%	94	55.3%
Help from Staff	1	0.6%	0	0.0%	1	0.6%
Unknown	6	3.5%	3	1.8%	9	5.3%

Table 30: Responses to POS (summary score and individual questions) in categories compared across gender for recently diagnosed patients (n=170). Missing data presented.

The majority (55.3%) of newly diagnosed patients completed the questionnaire with help from family or friends or by themselves (38.8%). Again very few patients required help from staff (0.6%).

All of the patients completing a full POS score (n=147) recorded at least one supportive care need being present. The overall mean POS score of 10.74 (SD 5.85, 95% CI 9.79-11.69) was higher in the newly diagnosed patients than the general clinic population. The median POS was 10. Comparison of newly diagnosed patients ($\bar{x}$=10.74) with those not diagnosed in the preceding six weeks ($\bar{x}$=8.93) demonstrated a significant mean POS difference of 1.81, 95% CI 0.49 to 3.13, p=0.007(Student's t test, 2 tailed).

Six out of ten of the issues assessed by POS had a median value of 0; two issues (pain and self-worth) had median values of 1. There were two issues identified by POS with a median value in the moderate or above category (personal anxiety and perceived support network anxiety). These issues were rated significantly higher in this newly diagnosed population compared to those outwith six weeks of diagnosis (Mann-Whitney U test): personal anxiety ($\bar{x}$=1.93, SD 1.35, median 2, p<0.001) and perceived anxiety within the patient's support network ($\bar{x}$=2.63, SD 1.23, median 3, p<0.001). The only other significant difference in POS items between newly diagnosed patients and patients who had not been diagnosed in the preceding six weeks was found to relate to practical matters requiring to be addressed (p=0.007). This latter difference may well relate to the initial lack of time for the service to identify and address such issues.

Prevalences of moderate to overwhelming issues were as follows: 123 patients (72.4%, 95%CI 65.2-78.5%) felt their support network was anxious, 91 (53.5%, 95% CI 46.0-60.9%) reported personal anxiety, 73 (42.9%, 95% CI 35.7-50.7%) pain, 60 (35.3%, 95% CI 28.5-42.7%) unmet information needs, 51 (30%, 95% CI 23.6%-37.3%) reduced self-esteem, 45 (26.4%, 95%CI 20.4-33.6%) practical matters needing addressed, 37 (21.8%, 95% CI 16.2-28.6%) were able to share feelings occasionally or not at all, 29 (17.1%, 95%CI 12.1%-23.4%) affected by 'other' symptoms, 22 (12.9%, 95% CI 8.7-18.8%) felt life was worthwhile only sometimes to not at all and only 17 (10%, 95% CI 6.3-15.4%) felt half or more of a day had been wasted through health care appointments.

6.2.2.1.1 Responses to Respiratory Symptoms, Service Views and Other Questions

Overall, 170 (48.2%) patients out of the total study population (n=353) completed an initial questionnaire within six weeks of diagnosis. Of these 170 patients, 160 (94.1%) competed all the respiratory questions, thus allowing a summary score to be calculated. Ten (5.9%) patients did not fully complete the respiratory questions but some have responded to a proportion of individual questions. Eighty-one (22.9%) patients out of 353 completed a satisfaction score. It should be noted that these questions were not included within year 1 and, as such, 177 (50.1%) patients did not complete a satisfaction score in year 1. Thus the 81 completed scores represent (76.4%) of the number of possible scores when Q1 < six weeks from diagnosis (n=106). Twenty-five out of 106 patients (23.6%) did not complete a full satisfaction score but some have completed a proportion of the individual questions. Summary statistics for respiratory symptom questions and service questions were tabulated (Table 31).

	N	Percentage	Mean	Standard Deviation	95% CI of mean	Median	Range
Patients with recent diagnosis (Q1<6 weeks from diagnosis) n=170							
Respiratory symptom summary score	160	94.1%	3.12	2.03	0.31	3	0-10
Dypsnoea	166	97.6%	1.56	1.07	0.16	2	0-4
Cough	163	95.9%	1.27	0.98	0.15	1	0-3
Haemoptysis	161	94.7%	0.32	0.76	0.12	0	0-3
Patients with recent diagnosis (Q1<6 weeks from diagnosis) n=106							
Satisfaction score	81	76.4%	1.27	1.47	0.32	1	0-7
Satisfaction with investigations	88	83.0%	0.48	0.73	0.15	0	0-3
Satisfaction with way diagnosis was given	88	83.0%	0.55	0.71	0.15	0	0-3
Satisfaction with follow-up	82	77.4%	0.30	0.46	0.10	0	0-1

Table 31: Summary statistics of overall and individual respiratory and satisfaction scores.

Percentage of responses to questions about respiratory symptoms, satisfaction, symptom occurrence, GP use, preferences regarding follow-up responses and perception of who is in charge have been displayed. Bar charts with 95% CI for responses to each item are displayed in Figure 14A and B.

A table showing symptom responses categorised into none-mild, moderate and severe-overwhelming and also service question responses is displayed (Table 32).

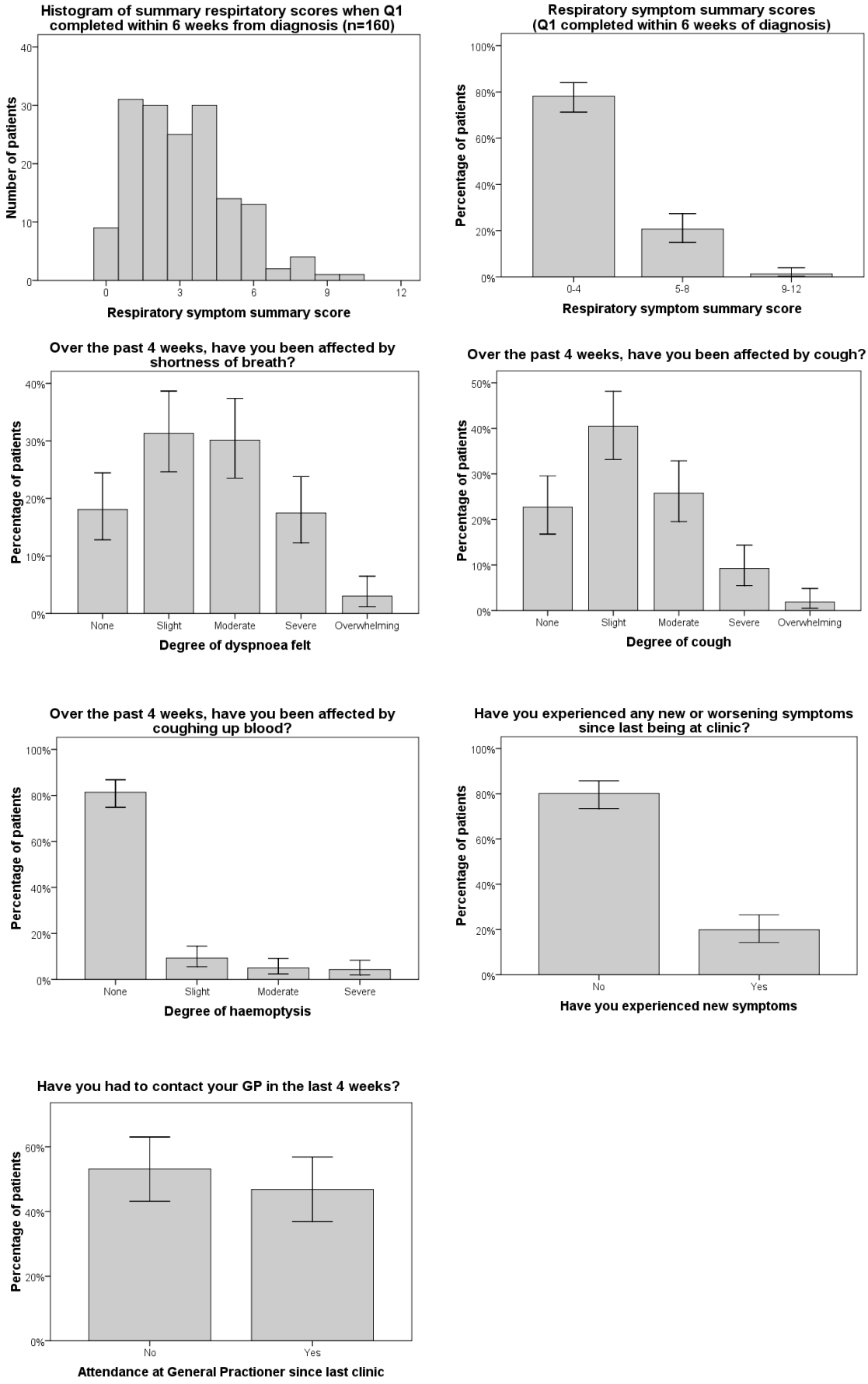
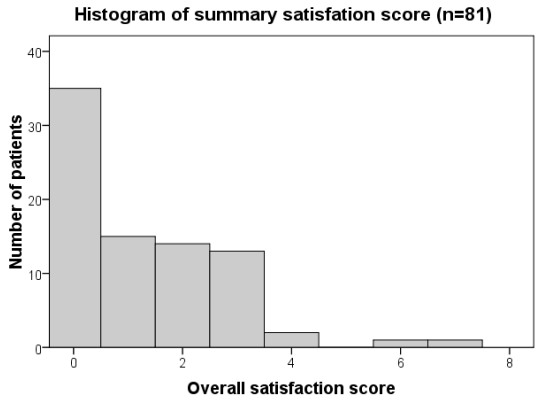
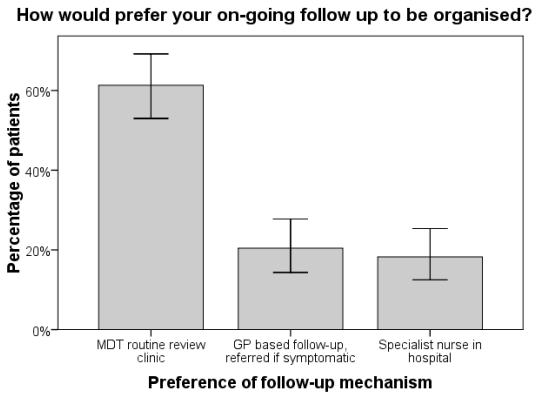
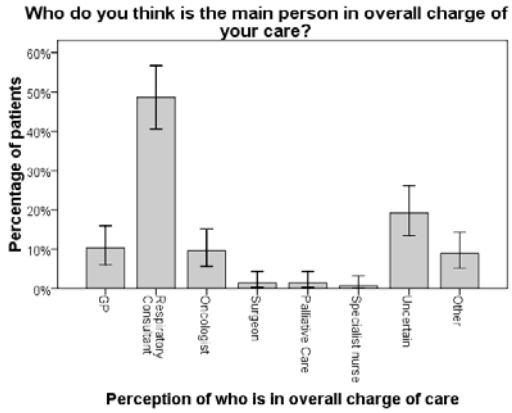


Figure 14A: Histogram and bar charts of patient responses to respiratory symptom and other symptom related questions (Q1<6 weeks of diagnosis). Percentages adjusted for missing data.







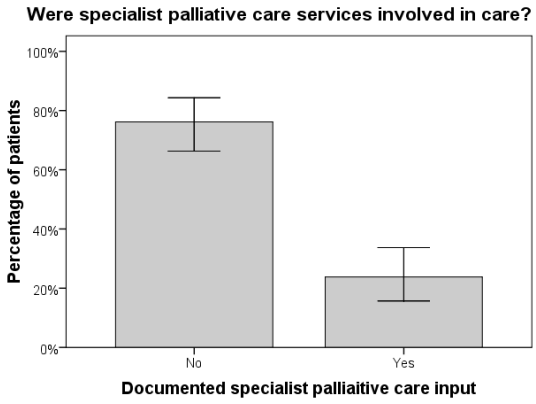


Figure 14B: Histogram and bar charts of patient responses to service questions (Q1<6 weeks of diagnosis). Percentages adjusted for missing data and 95% CI included.

Analysis of Respiratory and other symptom questions from Q1 < 6 weeks across gender

	Male		Female		Total	
	Number	%	Number	%	Number	%
Questionnaires						
Number of lung clinic questionnaires completed	84	49.4%	86	50.6%	170	100.0%
Number of fully completed respiratory questions	79	46.5%	81	47.6%	160	94.1%
Incomplete respiratory questions	5	2.9%	5	2.9%	10	5.9%
Summary Respiratotry Score	79	46.5%	81	47.6%	160	94.1%
0-4	60	35.3%	65	38.2%	125	73.5%
5-8	18	10.6%	15	8.8%	33	19.4%
9-12	1	0.6%	1	0.6%	2	1.2%
Missing	5	2.9%	5	2.9%	10	5.9%
Have you been affected by dyspnoea?	82	48.2%	84	49.4%	166	97.6%
None or slight	42	24.7%	40	23.5%	82	48.2%
Moderate	27	15.9%	23	13.5%	50	29.4%
Severe or overwhelming	13	7.6%	21	12.4%	34	20.0%
Missing	2	1.2%	2	1.2%	4	2.4%
Have you been affected by cough?	81	47.6%	82	48.2%	163	95.9%
None or slight	48	28.2%	55	32.4%	103	60.6%
Moderate	23	13.5%	19	11.2%	42	24.7%
Severe or overwhelming	10	5.9%	8	4.7%	18	10.6%
Missing	3	1.8%	4	2.4%	7	4.1%
Have you been affected by haemoptysis?	79	46.5%	82	48.2%	161	94.7%
None or slight	71	41.8%	75	44.1%	146	85.9%
Moderate	5	2.9%	3	1.8%	8	4.7%
Severe or overwhelming	3	1.8%	4	2.4%	7	4.1%
Missing	5	2.9%	4	2.4%	9	5.3%
Have you had any new or worsening symptoms since last clinic?	80	47.1%	81	47.6%	161	94.7%
No	65	38.2%	64	37.6%	129	75.9%
Yes	15	8.8%	17	10.0%	32	18.8%
Missing	4	2.4%	5	2.9%	9	5.3%
Have you had to contact your GP since last clinic?	42	24.7%	52	30.6%	94	55.3%
No	22	12.9%	28	16.5%	50	29.4%
Yes	20	11.8%	24	14.1%	44	25.9%
Missing	42	24.7%	34	20.0%	76	44.7%
Satisfaction summary Score	38	22.4%	43	25.3%	81	47.6%
0-4	37	21.8%	42	24.7%	79	46.5%
5-8	1	0.6%	1	0.6%	2	1.2%
9-12	0	0.0%	0	0.0%	0	0.0%
Missing	46	27.1%	43	25.3%	89	52.4%
How satisfied were you with the way tests were carried out?	39	22.9%	49	28.8%	88	51.8%
Very satisfied or satisfied	37	21.8%	45	26.5%	82	48.2%
Unsatisfied or very unsatisfied	2	1.2%	4	2.4%	6	3.5%
Missing	45	26.5%	37	21.8%	82	48.2%
How satisfied were you with the way your diagnosis was given?	39	22.9%	49	28.8%	88	51.8%
Very satisfied or satisfied	37	21.8%	44	25.9%	81	47.6%
Unsatisfied or very unsatisfied	2	1.2%	5	2.9%	7	4.1%
Missing	45	26.5%	37	21.8%	82	48.2%
How satisfied were you with the way you are being followed-up?	38	22.4%	44	25.9%	82	48.2%
Very satisfied or satisfied	38	22.4%	44	25.9%	82	48.2%
Unsatisfied or very unsatisfied	0	0.0%	0	0.0%	0	0.0%
Missing	46	27.1%	42	24.7%	88	51.8%
Do you feel you are seeing to many health care professionals	76	44.7%	81	47.6%	157	92.4%
No	70	41.2%	75	44.1%	145	85.3%
Yes	6	3.5%	6	3.5%	12	7.1%
Missing	8	4.7%	5	2.9%	13	7.6%
How would you prefer to be followed-up?	68	40.0%	69	40.6%	137	80.6%
MDT clinic with routine review	40	23.5%	44	25.9%	84	49.4%
GP based system, referred back if symptoms occur	16	9.4%	12	7.1%	28	16.5%
Hospital-based specialist nurse	12	7.1%	13	7.6%	25	14.7%
Missing	16	9.4%	17	10.0%	33	19.4%
Who do you think is in over all charge of your care?	68	40.0%	78	45.9%	146	85.9%
GP	8	4.7%	7	4.1%	15	8.8%
Respiratory Consultant	38	22.4%	33	19.4%	71	41.8%
Oncologist	3	1.8%	11	6.5%	14	8.2%
Surgeon	0	0.0%	2	1.2%	2	1.2%
Palliative Care Consultant	2	1.2%	0	0.0%	2	1.2%
Specialist nurse	1	0.6%	0	0.0%	1	0.6%
Uncertain	11	6.5%	17	10.0%	28	16.5%
Other	5	2.9%	8	4.7%	13	7.6%
Missing	16	9.4%	8	4.7%	24	14.1%
Has palliative care been involved in care?	39	22.9%	45	26.5%	84	49.4%
No	28	16.5%	36	21.2%	64	37.6%
Yes	11	6.5%	9	5.3%	20	11.8%
Missing	45	26.5%	41	24.1%	86	50.6%

Table 32: Responses to respiratory and other symptom questions (summary score and individual questions) and service-related questions compared across genders from Q1<6 weeks of diagnosis. Note: satisfaction questions not available in year 1.

One hundred and fifty-one of the 160 patients (94.4%) completed a respiratory score and reported at least one respiratory symptom. The only respiratory symptom identified as moderate or above was dyspnoea (median 2). The prevalences of moderate to overwhelming symptoms were as follows: dyspnoea 84 (49.4%, 95% CI 42.0-56.9%), cough 60 (35.3%, 95% CI 28.5-42.7%) and haemoptysis 15 (8.8%, 95% CI 5.4-14.0%).

When satisfaction was assessed, the majority of patients were either very satisfied or satisfied with the investigation process (82, 77%), diagnosis disclosure (81, 76%) and follow-up (82, 77%).

Most patients (75.9%) indicated no new or changing symptoms, and 25.9% had contacted their GP since their last clinic review. Most (145, 85.3%) did not feel they were seeing too many health care professionals, and almost half of patients (49.4%) preferred follow-up at the MDT clinic with routine review. However, 16.5% of patients would prefer a GP-led follow-up system and 14.7% a nurse-led follow-up; 19.4% did not express an opinion. Sixty-four (76.2%) patients did not have documented palliative care input (this was reviewed only in year 2/3, n=84). Most patients (41.8%) identified the respiratory consultant as in charge of care, 8.8% GP, 8.2% oncologist and 3.0% surgeon, palliative care or specialist nurse, 24.1% were uncertain or suggested 'other' and 14.1% did not reply.

6.2.3 Last Questionnaires Completed Within Three Months Prior to All-Cause Death

6.2.3.1 Responses to POS Questions

Of the 215 patients who died, 121 (56.3%) had completed a questionnaire within the three months prior to death. Out of these 121, 109 (90.1%) completed all the POS questions allowing a summary score out of 40 to be calculated. Twelve (9.9%) patients did not fully complete the POS questions but some responded to a proportion of individual questions. Summary statistics are tabulated below (Table 33).

	N	Percentage	Mean	Standard Deviation	95% CI of mean	Median	Range
Palliative Outcome Scale summary score	109	90.1%	11.40	6.30	1.18	11	0-27
Pain	117	96.7%	1.68	1.33	0.24	2	0-4
Other symptoms	113	93.4%	1.00	1.10	0.20	1	0-4
Personal anxiety	113	93.4%	1.79	1.34	0.25	2	0-4
Perceived anxiety within support network	114	94.2%	2.40	1.35	0.25	3	0-4
Ability to share	115	95.0%	0.91	1.23	0.23	0	0-4
Life-worth	114	94.2%	0.75	1.05	0.19	0	0-4
Self-worth	115	95.0%	1.63	1.40	0.26	1	0-4
Information	114	94.2%	0.72	1.20	0.22	0	0-4
Practical issues	114	94.2%	0.68	0.98	0.18	0	0-3
Time use	115	95.0%	0.16	0.45	0.08	0	0-2
Form completion	115	95.0%	0.67	0.54	0.10	1	0-2

Table 33: Summary statistics of overall and individual POS scores in patients less than three months prior to death (from any cause).

POS individual question responses and summary scores alongside patient-rated PS are displayed in Figure 15. Individual bar charts of responses to each question with 95% CI are displayed in Appendix 7 (Figure 23A and B).

Responses categorised into none-mild, moderate and severe across groupings of Q1=QF and when Q1≠QF are tabulated. Comparisons across the groupings are included (Table 34).

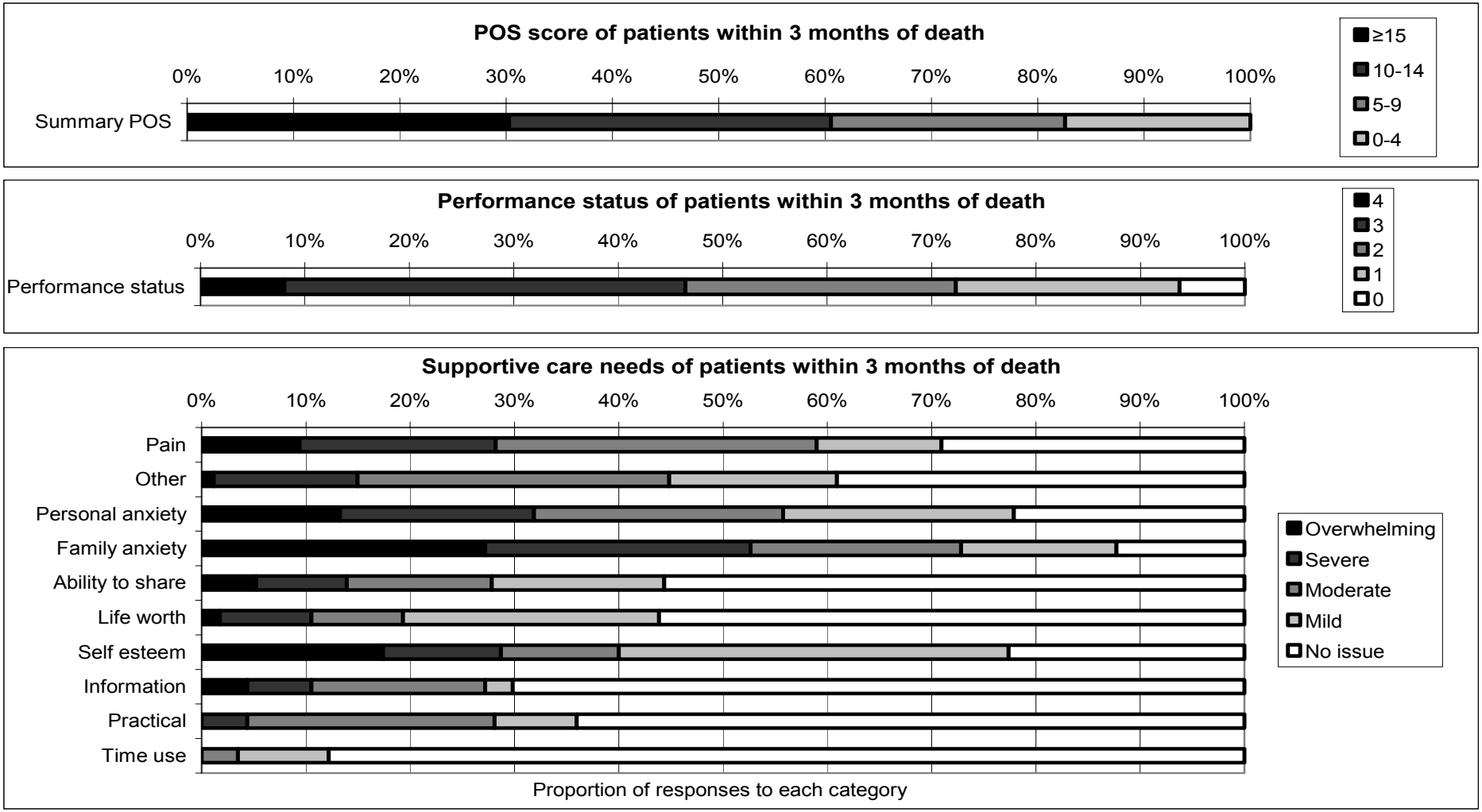


Figure 15: Stacked bar chart showing POS scores, PS and POS responses for patients three months from death. Percentages adjusted for missing data.

Analysis of Palliative Outcome Scale from Final Questionnaire (QF) when death occurs within 3months from POS									
	Final Questionniare when =Q1			Final Questionnaire when not =Q1			Total		
	Number	%	X2	Number	%	X2	Number	%	
POS									
Number of Questionnaires completed	54	44.6%		67	55.4%		121	100.0%	
Number of fully completed POS questions	46	38.0%		63	52.1%		109	90.1%	
Incomplete POS questions	8			4			12	9.9%	
Summary POS Score	46	38.0%		63	52.1%		109	90.1%	
0-4	5	4.1%	1.14	14	11.6%	0.83	19	15.7%	
5-9	11	9.1%	0.07	13	10.7%	0.05	24	19.8%	
10-14	13	10.7%	0.06	20	16.5%	0.05	33	27.3%	X2= 3.376
≥15	17	14.0%	0.68	16	13.2%	0.50	33	27.3%	df= 3
Missing	8	6.6%		4	3.3%		12	9.9%	p= 0.34
Have you been affected by pain?	52	43.0%		65	53.7%		117	96.7%	
None or slight	24	19.8%	0.33	24	19.8%	0.27	48	39.7%	
Moderately	13	10.7%	0.56	23	19.0%	0.45	36	29.8%	X2= 1.626
Severe or overwhelming	15	12.4%	0.01	18	14.9%	0.01	33	27.3%	df= 2
Missing	2	1.7%		2	1.7%		4	3.3%	p= 0.44
Have any other symptoms been affecting how you feel?	50	41.3%		63	52.1%		113	93.4%	
None or slight	32	26.4%	0.02	42	34.7%	0.01	74	61.2%	
Moderately	9	7.4%	0.55	17	14.0%	0.43	26	21.5%	X2= 3.828
Severe or overwhelming	9	7.4%	1.36	4	3.3%	1.46	13	10.7%	df= 2
Missing	4	3.3%		4	3.3%		8	6.6%	p= 0.15
Have you felt anxious or worried about your illness or treatment?	50	41.3%		63	52.1%		113	93.4%	
None or slight	14	11.6%	2.98	36	29.8%	2.37	50	41.3%	
Moderate	14	11.6%	0.35	13	10.7%	0.28	27	22.3%	X2= 10.133
High anixiety (severe-overwhelming)	22	18.2%	2.31	14	11.6%	1.84	36	29.8%	df= 2
Missing	0	0.0%		4	3.3%		4	3.3%	p= 0.01
Have any of your friends or family about your illness or treatment?	50	41.3%		64	52.9%		114	94.2%	
None or slight	8	6.6%	9.61	44	36.4%	7.51	52	43.0%	
Moderate	7	5.8%	0.03	8	6.6%	0.02	15	12.4%	X2= 28.987
High anixiety (severe-overwhelming)	35	28.9%	3.97	12	9.9%	7.84	47	38.8%	df= 2
Missing	4	3.3%		3	2.5%		7	5.8%	p= 0.00
Have you been able to share how you are feeling with family or friends?	51	42.1%		64	52.9%		115	95.0%	
Most or as much as wanted	39	32.2%	0.13	44	36.4%	0.10	83	68.6%	
Sometimes	8	6.6%	0.12	8	6.6%	0.09	16	13.2%	X2= 2.868
Ocassionnally or not at all	4	3.3%	1.35	12	9.9%	1.08	16	13.2%	df= 2
Missing	3	2.5%		3	2.5%		6	5.0%	p= 0.24
Have you felt life was worthwhile?	50	41.3%		64	52.9%		114	94.2%	
Yes to most of time	37	30.6%	0.28	55	45.5%	0.22	92	76.0%	
Sometimes	5	4.1%	0.09	5	4.1%	0.07	10	8.3%	X2= 3.184
Ocassionnally or not at all	8	6.6%	1.42	4	3.3%	1.11	12	9.9%	df= 2
Missing	4	3.3%		3	2.5%		7	5.8%	p= 0.20
Have you felt good about yourself?	51	42.1%		64	52.9%		115	95.0%	
Yes to most of time	26	21.5%	0.69	43	35.5%	0.55	69	57.0%	
Sometimes	6	5.0%	0.01	7	5.8%	0.01	13	10.7%	X2= 3.599
Ocassionnally or not at all	19	15.7%	1.30	14	11.6%	1.04	33	27.3%	df= 2
Missing	3	2.5%		3	2.5%		6	5.0%	p= 0.17
How much information has been given?	50	41.3%		64	52.9%		114	94.2%	
Full info to full info but some hard to understand	34	28.1%	0.16	49	40.5%	0.12	83	68.6%	
Info on request but wanted more	10	8.3%	0.33	9	7.4%	0.26	19	15.7%	X2= 1.060
Very little to no information	6	5.0%	0.10	6	5.0%	0.08	12	9.9%	df= 2
Missing	4	3.3%		3	2.5%		7	5.8%	p= 0.59
Have practical matters, relating to your illness, been addressed?	50	41.3%		64	52.9%		114	94.2%	
No issues or issues addressed	33	27.3%	0.24	49	40.5%	0.19	82	67.8%	
Practical issues are currently being addressed	16	13.2%	1.46	11	9.1%	1.14	27	22.3%	X2= 4.192
Practical issues exist which have not been addressed	1	0.8%	0.65	4	3.3%	0.51	5	4.1%	df= 2
Missing	4	3.3%		3	2.5%		7	5.8%	p= 0.12
How much time do you feel has been wasted through healthcare?	51	42.1%		64	52.9%		115	95.0%	
None at all	44	36.4%	0.01	57	47.1%	0.01	101	83.5%	
Up to half a day wasted	4	3.3%	0.04	6	5.0%	0.03	10	8.3%	X2= 1.624
More than half a day wasted	3	2.5%	0.85	1	0.8%	0.68	4	3.3%	df= 2
Unknown	3	2.5%		3	2.5%		6	5.0%	p= 0.44
Form Completion	51	42.1%		64	52.9%		115	95.0%	
Self	17	14.0%	0.14	25	20.7%	0.11	42	34.7%	
Help from family	33	27.3%	0.19	36	29.8%	0.15	69	57.0%	X2= 1.200
Help from Staff	1	0.8%	0.34	3	2.5%	0.27	4	3.3%	df= 2
Unknown	3	2.5%		3	2.5%		6	5.0%	p= 0.55

Table 34: Responses to POS (summary score and individual questions) in categories compared between all final questionaires (QF), and final questionnaires from patients completing greater than one (QF≠Q1) in patients who died within three months of questionnaire completion.

In final questionnaires completed within three months of death by any cause, 69 (57%) patients had help from family and friends and 42 (34.7%) completed the form themselves.

A difference between questionnaire grouping (QF=Q1 versus QF≠Q1) was observed for both personal anxiety (X^2=10.133, df=2, p=0.01) and perceived support network anxiety (X^2=28.987, df=2, p<0.01). For both items, more anxiety was recorded in the group in whom their first questionnaire was also QF. No other differences were observed in POS responses between the questionnaire groups.

One hundred and eight (99.1%) patients completing a full POS score recorded at least one supportive care need being present. The overall mean POS score was 11.40 (SD 6.3, 95% CI 10.22-12.58) and the median was 11. Mean POS scores were higher from QF in those with three months or less to live ($\bar{x}$ =11.40 SD=6.304) than QF completed by patients with greater than three months to live but who subsequently died ($\bar{x}$ =9.69 SD=5.656). However, this did not reach statistical significance: mean difference 1.716 (95% CI -0.009 to 2.441, p=0.51).

Five out of ten of the issues assessed by POS had a median value of 0; two issues (self-worth and 'other' symptoms) had a median value of 1. There were three issues identified by POS with a median value in the moderate or above category: personal anxiety (median 2), support network anxiety (median 3) and pain (median 2).

Prevalences of moderate to overwhelming issues were as follows: pain 69 (57.1%, 95% CI 48.1-65.5%), personal anxiety 63 (52.1%, 95% CI 43.2-60.8%), perception of support network anxiety 62 (51.2%, 95%CI 42.4-60.0%), self-esteem 46 (38.0%, 95% CI 29.9-46.9%), 'other' symptoms 39 (32.2%, CI 95% 24.6-41.0%), ability to share 32 (26.4%, 95% CI 19.4-34.9%), practical issues 32 (26.4%, 95% CI 19.4-34.9%), information 31 (25.6%, 95% CI 18.7-34.1%), life-worth 22 (18.2%, 95% CI 12.3-26%) and time wasted 14 (11.6%, 95% CI 7.0-18.5%). Thus, pain was found to be the most prevalent issue in this group of patients.

6.2.3.2 Responses to Respiratory Symptoms, Service Views and Other Questions

Overall, 215 patients (60.1%) out of 353 died during the study period. Of these 215 patients, 121 (56.20%) completed a QF within three months prior to death. One hundred and fourteen (94.2%) patients completed all the respiratory questions allowing a summary score to be calculated. Seven (5.3%) patients did not fully complete the respiratory questions but some responded to a proportion of individual questions.

Fifty-six (15.9%) patients out of 353 completed a satisfaction score. It should be noted that these questions were not included within year 1 and, as such, 177 (50.1%) patients did not complete a satisfaction score in year 1. Thus, the 56 completed scores represent 74.7% of the number of possible scores for QF<3 months from any cause of death (n=75). Nineteen out of 75 (25.3%) patients did not complete a full satisfaction score but some have completed a proportion of individual questions. Summary statistics for respiratory symptom questions and service questions were tabulated (Table 35).

	N	Percentage	Mean	Standard Deviation	95% CI of mean	Median	Range
Deceased patients with QF<3months from death n=121							
Respiratory symptom summary score	114	94.2%	3.54	2.24	0.41	4	0-10
Dypsnoea	117	96.7%	1.92	1.23	0.22	2	0-4
Cough	115	95.0%	1.40	1.19	0.22	1	0-4
Haemoptysis	113	93.4%	0.25	0.62	0.11	0	0-3
Deceased patients with QF<3months from death n=121							
Satisfaction score	56	46.3%	1.71	1.47	0.39	1	0-6
Satisfaction with investigations	59	48.8%	0.47	0.63	0.16	0	0-3
Satisfaction with way diagnosis was given	59	48.8%	0.68	0.54	0.14	1	0-2
Satisfaction with follow-up	56	46.3%	0.52	0.57	0.15	0	0-2

Table 35: Summary statistics of overall and individual respiratory and satisfaction scores.

Individual bar charts with 95% CI for all non-POS item responses are displayed (Figure 16A and B). A table showing symptom responses categorised into none-mild, moderate and severe-overwhelming and also service question responses is displayed (Table 36).

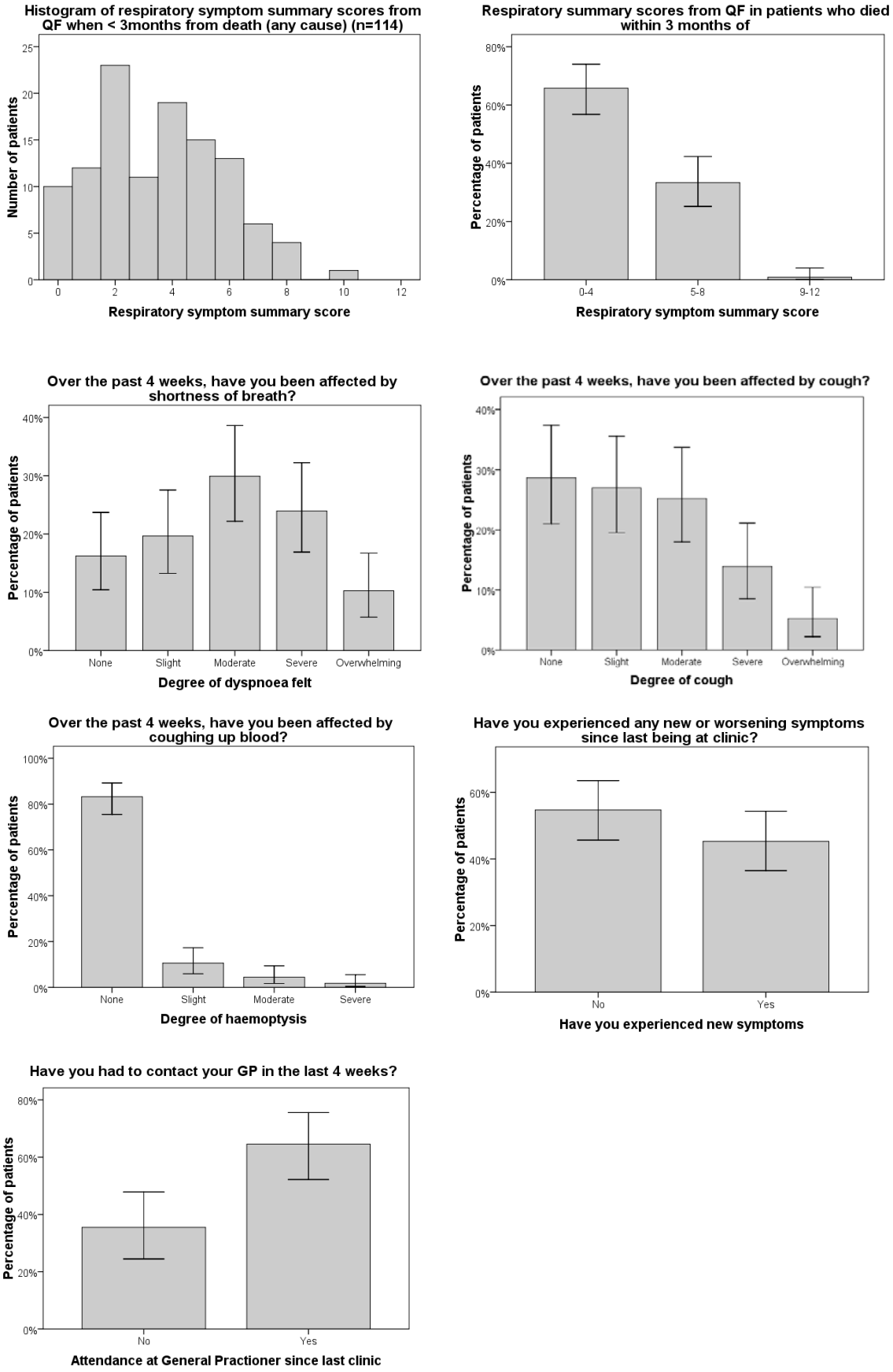


Figure 16A: Histogram and bar charts of patient responses to respiratory symptom and other symptom related questions (QF completed in patients who died of any cause within three months of completing QF). Percentages adjusted for missing data.

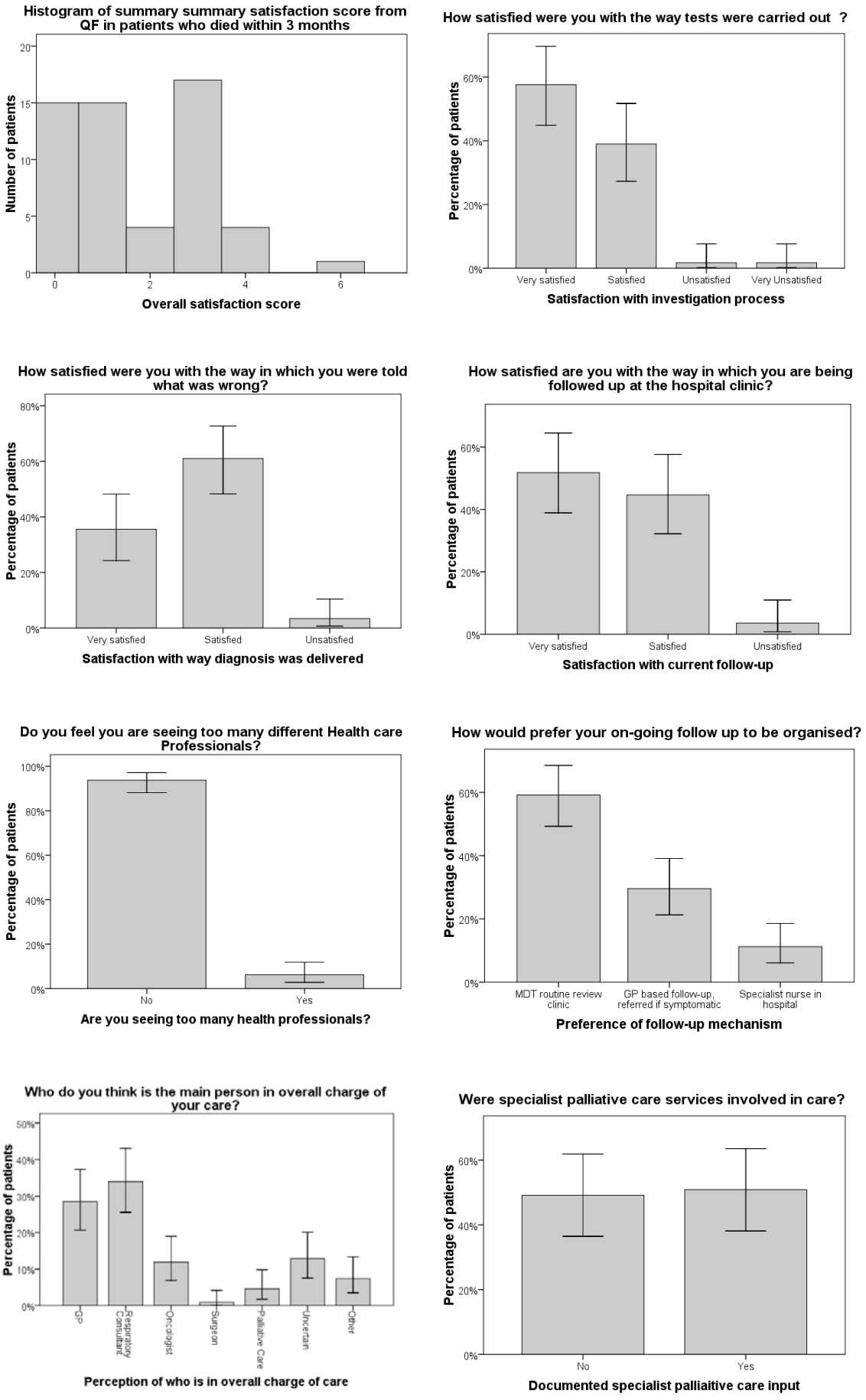


Figure 16B: Patient responses to service questions (QF in patients who completed QF within three months of death). Percentages adjusted for missing data and 95% CI included.

Analysis of Respiratory and other symptom questions from Qf within 3 months of when death (all cause) has occurred within study period									
	Final Questionnaire when =Q1			Final Questionnaire when not equal to Q1			Total		
	Number	%	X2	Number	%	X2	Number	%	
Questionnaires									
Number of lung clinic questionnaires completed	54	44.6%		67	55.4%		121	100.0%	
Number of fully completed respiratory questions	50	41.3%		64	52.9%		114	94.2%	
Incomplete respiratory questions	4	3.3%		3	2.5%		7	5.8%	
Summary Respiratotry Score	50	41.3%		64	52.9%		114	94.2%	
0-4	32	26.4%	0.02	43	35.5%	0.02	75	62.0%	
5-8	17	14.0%	0.01	21	17.4%	0.01	38	31.4%	X2= 1.34
9-12	1	0.8%	0.72	0	0.0%	0.56	1	0.8%	df= 2
Missing	4	3.3%		3	2.5%		7	5.8%	p= 0.51
Have you been affected by dyspnoea?	52	43.0%		65	53.7%		117	96.7%	
None or slight	19	15.7%	0.01	23	19.0%	0.00	42	34.7%	
Moderate	14	11.6%	0.16	21	17.4%	0.12	35	28.9%	X2= 0.44
Severe or overwhelming	19	15.7%	0.08	21	17.4%	0.07	40	33.1%	df= 2
Missing	2	1.7%		2	1.7%		4	3.3%	p= 0.80
Have you been affected by cough?	51	42.1%		64	52.9%		115	95.0%	
None or slight	24	19.8%	0.01	40	33.1%	0.01	64	52.9%	
Moderate	15	12.4%	0.10	21	17.4%	0.06	36	29.8%	X2= 0.24
Severe or overwhelming	12	9.9%	0.03	21	17.4%	0.02	33	27.3%	df= 2
Missing	3	2.5%		3	2.5%		6	5.0%	p= 0.89
Have you been affected by haemoptysis?	50	41.3%		63	52.1%		113	93.4%	
None or slight	46	38.0%	0.02	60	49.6%	0.01	106	87.6%	
Moderate	3	2.5%	0.28	2	1.7%	0.22	5	4.1%	X2= 0.56
Severe or overwhelming	1	0.8%	0.01	1	0.8%	0.01	2	1.7%	df= 2
Missing	4	3.3%		4	3.3%		8	6.6%	p= 0.76
Have you had any new or worsening symptoms since last clinic?	51	42.1%		66	54.5%		117	96.7%	
No	34	28.1%	1.33	30	24.8%	1.03	64	52.9%	X2= 5.22
Yes	17	14.0%	1.61	36	29.8%	1.25	53	43.8%	df= 1
Missing	28	23.1%		31	25.6%		59	48.8%	p= 0.03
Have you had to contact your GP since last clinic?	26	21.5%		36	29.8%		62	51.2%	
No	9	7.4%	0.01	13	10.7%	0.00	22	18.2%	X2= 0.01
Yes	17	14.0%	0.00	23	19.0%	0.00	40	33.1%	df= 1
Missing	28	23.1%		31	25.6%		59	48.8%	p= 1.00
Satisfaction summary Score	22	18.2%		34	28.1%		56	46.3%	
0-4	21	17.4%		34	28.1%		55	45.5%	
5-8	1	0.8%		0	0.0%		1	0.8%	X2= na
9-12	0	0.0%		0	0.0%		0	0.0%	df= 2
Missing	32	26.4%		33	27.3%		65	53.7%	p= na
How satisfied were you with the way tests were carried out?	25	20.7%		34	28.1%		59	48.8%	
Very satisfied or satisfied	24	19.8%	0.00	33	27.3%	0.00	57	47.1%	X2= 0.05
Unsatisfied or very unsatisfied	1	0.8%	0.03	1	0.8%	0.02	2	1.7%	df= 1
Missing	29	24.0%		33	27.3%		62	51.2%	p= 1.00
How satisfied were you with the way your diagnosis was given?	25	20.7%		34	28.1%		59	48.8%	
Very satisfied or satisfied	25	20.7%	0.03	32	26.4%	0.02	57	47.1%	X2= 1.52
Unsatisfied or very unsatisfied	0	0.0%	0.85	2	1.7%	0.62	2	1.7%	df= 1
Missing	29	24.0%		33	27.3%		62	51.2%	p= 0.50
How satisfied were you with the way you are being followed-up?	22	18.2%		34	28.1%		56	46.3%	
Very satisfied or satisfied	22	18.2%	0.03	32	26.4%	0.02	54	44.6%	X2= 1.34
Unsatisfied or very unsatisfied	0	0.0%	0.79	2	1.7%	0.51	2	1.7%	df= 1
Missing	32	26.4%		33	27.3%		65	53.7%	p= 0.51
Do you feel you are seeing to many health care professionals	50	41.3%		62	51.2%		112	92.6%	
No	46	38.0%	0.02	59	48.8%	0.01	105	86.8%	X2= 0.47
Yes	4	3.3%	0.25	3	2.5%	0.20	7	5.8%	df= 1
Missing	4	3.3%		5	4.1%		9	7.4%	p= 0.49
How would you prefer to be followed-up?	38	31.4%		60	49.6%		98	81.0%	
MDT clinic with routine review	21	17.4%	0.10	37	30.6%	0.06	58	47.9%	
GP based system, referred back if symptoms occur	11	9.1%	0.01	18	14.9%	0.00	29	24.0%	X2= 1.32
Hospital-based specialist nurse	6	5.0%	0.71	5	4.1%	0.45	11	9.1%	df= 2
Missing	16	13.2%		7	5.8%		23	19.0%	p= 0.52
Who do you think is in over all charge of your care?	48	39.7%		61	50.4%		109	90.1%	
GP	13	10.7%	0.03	18	14.9%	0.02	31	25.6%	
Respiratory Consultant	17	14.0%	0.03	20	16.5%	0.02	37	30.6%	
Oncologist	1	0.8%	3.90	12	9.9%	3.07	13	10.7%	
Surgeon	0	0.0%	0.50	1	0.8%	0.35	1	0.8%	
Palliative Care Consultant	1	0.8%	0.66	4	3.3%	0.52	5	4.1%	
Specialist nurse	0	0.0%	na	0	0.0%	na	0	0.0%	
Uncertain	9	7.4%	1.30	5	4.1%	1.03	14	11.6%	X2= na
Other	7	5.8%	3.43	1	0.8%	2.70	8	6.6%	df= 7
Missing	6	5.0%		6	5.0%		12	9.9%	p= na
Has palliative care been involved in care?	28	23.1%		29	24.0%		57	47.1%	
No	12	9.9%	0.22	16	13.2%	0.22	28	23.1%	X2= 0.86
Yes	16	13.2%	0.22	13	10.7%	0.21	29	24.0%	df= 1
Missing	26	21.5%		38	31.4%		64	52.9%	p= 0.43

Table 36: Responses to respiratory and other symptom questions (summary score and individual questions) and service related questions compared between QF when equal to Q1 and when not. QF in patients who died within three months of completing QF. Note: satisfaction questions not available in year 1.

A respiratory score was completed and at least one respiratory symptom reported for for 104 (91.0%) of the 114. The only respiratory symptom identified as moderate or above was dyspnoea (median 2).

Prevalences of moderate to overwhelming symptoms were: dyspnoea 75 (62.0%, 95% CI 53.1-70.1%), cough 69 (57.1%, 95% CI 48.1-65.5%) and haemoptysis 7 (5.8%, 95% CI 2.8-11.5%). Many (52.9%) patients indicated no new or changing symptoms and 43.8% had contacted their GP since their last clinic review. A significant difference

across questionnaire groups (QF and QF≠Q1) was observed in 'new or changed symptoms' (p=0.03)

When satisfaction was assessed, the majority of patients were either very satisfied or satisfied with the investigation process: diagnosis disclosure 57 (76%) and follow-up 54 (72%). Most (105, 86.8%) did not feel they were seeing too many health care professionals, and just under half of patients (47.9%) preferred follow-up at the MDT clinic with routine review. However, 24.0% of patients would prefer a GP-led follow-up system and 9.1% a nurse-led follow-up; 19% did not express an opinion. In those reviewed, 28 (49%) patients did not have documented palliative care input (this was reviewed only in year 2, n=57). Many (30.6%) patients identified the respiratory consultant as in charge of care, 25.6% GP, 10.7% oncologist and 4.9% surgeon, palliative care or specialist nurse, 18.2% were uncertain or suggested 'other' and 9.9% did not reply.

6.2.4 Main Issues Indicated by Free Text in POS

Within the POS questionnaire, the free text question 'If any, what have been your main problems in the last 4 weeks?' invites the patients to record the main issues affecting them. The responses to this question have been tabulated (Table 37).

	All patients' initial Questionnaire (Q1) n=353		Recent diagnosis (Q1 <6 weeks from diagnosis) n=170		All patients who died and QF within 3 months of death n=121	
	Number	Percentage	Number	Percentage	Number	Percentage
Dyspnoea	20	5.7%	14	8.2%	15	12.4%
Pain	16	4.5%	8	4.7%	9	7.4%
Cough	4	1.1%	0	0.0%	4	3.3%
Fatigue	7	2.0%	5	2.9%	3	2.5%
Nausea	4	1.1%	3	1.8%	3	2.5%
Anxiety	1	0.3%	1	0.6%	0	0.0%
Depression	0	0.0%	0	0.0%	0	0.0%
Treatment Side effects	1	0.3%	0	0.0%	0	0.0%
Weight loss	2	0.6%	1	0.6%	0	0.0%
Sweats	1	0.3%	1	0.6%	1	0.8%
Constipation	0	0.0%	0	0.0%	1	0.8%
Altered appetite	1	0.3%	0	0.0%	0	0.0%
Other	3	0.8%	2	1.2%	3	2.5%

Table 37: Summarised free text responses to the question 'If any, what have been your main problems in the last 4 weeks?' for different groupings of patients.

Within the category of 'other', free text responses included: bleeding, toe fracture, altered speech, oedema, balance issues, memory problems and difficulty walking (some patients reported more than one issue). Dyspnoea was the most frequently cited 'main issue' in each grouping. The second most frequent issue cited was pain.

6.2.5 Free Text Responses Outwith POS

Within the non-POS sections of the questionnaire, the free text question 'Have you had to contact your GP in the last 4 weeks? If so, why?' invites the patients to record the main reasons for attending their GP. The responses to this question have been tabulated (Table 38).

	All patients' initial Questionnaire (Q1)		Recent diagnosis (Q1 <6 weeks from diagnosis)		All patients who died and QF within 3 months of death	
	Number	Percentage	Number	Percentage	Number	Percentage
Dyspnoea	5	1.4%	3	1.8%	7	5.8%
Pain/Analgesics	11	3.1%	5	2.9%	6	5.0%
Cough	4	1.1%	2	1.2%	1	0.8%
Fatigue	0	0.0%	0	0.0%	0	0.0%
Nausea	1	0.3%	1	0.6%	2	1.7%
Anxiety	0	0.0%	0	0.0%	0	0.0%
Depression	0	0.0%	0	0.0%	0	0.0%
Treatment Side effects	0	0.0%	0	0.0%	0	0.0%
Weight loss	2	0.6%	1	0.6%	1	0.8%
Other	5	1.4%	5	2.9%	0	0.0%
Routine Follow-up	7	2.0%	2	1.2%	8	6.6%
Vaccination	4	1.1%	2	1.2%	0	0.0%
Practical conerns	1	0.3%	0	0.0%	1	0.8%
Discussion/Information	3	0.8%	2	1.2%	0	0.0%
Chest Infection	4	1.1%	2	1.2%	2	1.7%
Other Infections	3	0.8%	1	0.6%	2	1.7%
"Unwell"	2	0.6%	1	0.6%	1	0.8%
Medication/Script	8	2.3%	6	3.5%	2	1.7%

Table 38: Summarised free text responses to the question 'Have you had to contact your GP in the last 4 weeks? If so, why?' evaluated within different groupings of patients.

Within the 'other' category, responses included: rash, new lumps, bleeding, dyspepsia, high potassium, road accident, insomnia, smoking cessation advice, co-morbid conditions, jaundice and sick lines.

6.2.6 Comparison of LCQ Items Across Groupings

The median scores and their 95% CI for individual items in each grouping have been compared to the general population using Mann-Whitney U tests. The results are tabulated below (Table 39).

	Grouping of patients										
	General		New diagnosis			QF all cause mortality			QF <3 months from all death		
Physical	Median	95% CI	Median	95% CI	p value	Median	95% CI	p value	Median	95% CI	p value
Pain	1	1-1	1	1-2	0.55	2	1-2	0.13	2	1-2	**0.01**
Other	0	0-0	0	0-0	0.59	0	0-1	0.38	1	0-1	**0.03**
Dyspnoea	2	1-2	2	1-2	0.89	2	2-2	**<0.01**	2	2-2	**0.02**
Cough	1	1-1	1	1-1	0.51	1	1-1	0.87	1	1-2	0.65
Haemoptysis	0	0-0	0	0-0	**0.02**	0	0-0	0.74	0	0-0	0.40
Psycho-emotional											
Personal anxiety	1	1-2	2	1-2	<0.001	2	1-2	0.29	2	1-2	0.31
Support anxiety	2	2-3	3	3-3	<0.001	2	2-3	0.05	3	2-3	0.28
Self worth	1	1-1	1	0-0	0.79	1	1-1	0.15	1	1-1	0.37
Life worth	0	0-0	0	1-1	0.75	0	0-1	**0.03**	0	0-1	0.97
Ability to share	0	0-0	0	0-0	0.60	0	0-0	0.17	0	0-1	**0.04**
Social											
Practical	0	0-0	0	0-0	0.01	0	0-0	1.00	0	0-0	0.38
Information	0	0-0	0	0-0	0.37	0	0-0	0.89	0	0-0	0.41
Time	0	0-0	0	0-0	0.83	0	0-0	0.66	0	0-0	0.98
Satisfaction											
Investigations	0	0-0	0	0-0	0.76	0	0-1	0.50	0	0-1	0.92
Diagnosis	0	0-1	0	0-0	0.59	1	0-1	**0.01**	1	1-1	**0.01**
Follow-up	0	0-0	0	0-0	0.29	0	0-1	**0.03**	0	0-1	0.12
Performance Status	1	1-2	1	1-2	0.73	2	2-3	<0.001	2	2-3	<0.001

Table 39: Comparison of physical symptoms, psycho-emotional issues, social issues, satisfaction and performance status of different groupings to overall general clinic population (comparison by Mann-Whitney U tests).

6.2.7 Performance Status

Performance status is not evaluated in the patient version of POS. It can be assessed if the staff version is used concurrently. Patients in this study were asked to rate their own current performance status using the ECOG scale within the LCQ. Within the clinic, 333 patients (94.3%) and 160 (94.1%) newly diagnosed patients completed this item in their first questionnaire. One hundred and twelve (92.6%) patients who died within three months of QF completion responded to this item. These have been displayed in Figure 17. A table showing PS categorised into 0-2 and 3-4 is shown below; Fisher's exact test was used to assess for difference of each grouping from all patients (Table 40).

	Performance Status Category					
	0-2		3-4		Compared	Compared
	Count	%	Count	%	to general	to new
All patients	240	72.1%	93	27.9%		p=1.0
Newly diagnosed	116	72.5%	44	27.5%	p=1.0	
All cause death (<3 months)	60	53.6%	52	46.4%	p<0.001	p<0.001

Table 40: Table of current ECOG PS, patient-rated.

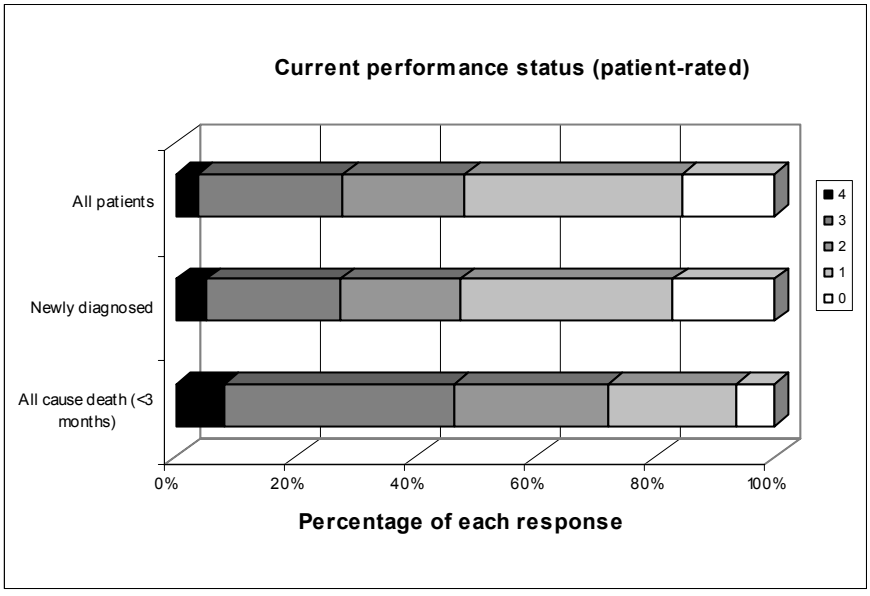


Figure 17: Stacked bar chart showing percentage response for each category of patient-rated, current ECOG performance status (4, 3, 2, 1, 0) for each grouping of patients. Percentages adjusted for missing data.

There was no difference found between the general clinic and newly diagnosed patients' PS. Those who subsequently died within three months of completing the LCQ had significantly poorer PS than the general clinic population and newly diagnosed patients.

6.3 Discussion

6.3.1 Questionnaire Response

There was a good response to the questionnaire with 353 patients returning at least one questionnaire. Around 200-250 new patients are referred to Stobhill each year for investigation of lung cancer. Of these referrals, approximately 130 are diagnosed with lung cancer. Therefore, in 30 months around 325 new diagnoses may be made. (Audit figures from Stobhill lung cancer service in 2008 reported 155 new patients, of which 128 had confirmed lung cancer (28 NSCLC, 25 SCLC and 25 clinical lung cancer)). Over the 30 months studied, 170 patients diagnosed within the previous six weeks responded (approximately 52% of possible newly diagnosed patients) and 121 patients completed the LCQ within three months of death. The majority of patients completed the forms by themselves or with some help from their family or friends. In comparison to many studies assessing symptoms and supportive care needs of patients with lung cancer, both the total number of patients participating and the response rate were good.

6.3.2 Supportive Care Needs Measured by the Palliative Outcome Scale

Previous studies using POS have reported findings in different ways and have studied heterogeneous groups of patients (i.e. multiple cancer sites, different settings and some non-cancer). The majority of previous POS study populations contain a proportion of lung cancer patients. Lung cancer patients have been reported to have high levels of symptom burden and unmet supportive care needs.[13, 157] In the current study, at least one unmet supportive care need was reported in 97.4% of all patients attending clinic, 100% of new diagnosis patients and 99.1% of those within three months of death. The mean scores for POS were 9.81 (CI 9.15-10.47), 10.74 (CI 9.79-11.69) and 11.40 (CI 10.22-12.58) for all patients, newly diagnosed patients and patients who died within three months of LCQ completion, respectively. Mean POS scores have been previously reported in the cancer setting of 15.9 by Bausewein et al[219] (22 lung cancer patients in a study group of 118 German cancer patients) and 8.04 by Higginson[215] (11 lung cancer patients in a study population of 66 palliative care patients). Other studies utilising POS do not report a mean summative score. No previous study has reported a median for the summative POS score. In this study, the median POS summative scores were 9, 10 and 11 for all patients, newly diagnosed patients and patients who died within three months of completing the LCQ, respectively. Bausewein et al[219] also report a range of

summative POS scores of 3-31; in this study we observed an overall range of 0-27. The findings from this study and previous studies have been tabulated below (Table 41).

	Eisenchlas et al, 2008	Bausewein et al, 2005	Stevens et al, 2005	Higginson, 2004	Hearn & Higginson, 1999	All Patients (Current Study)	Q1<6 weeks from Diagnosis (Current Study)	Qf<3months from death (Current Study)
Patient group studied	Argentina, Cancer	German, Cancer	UK, Cancer	UK, mainly cancer, some non-cancer	UK, Palliative care patients	Lung Cancer	Lung Cancer	Lung Cancer
Number of lung cancer patients	11of 65	22 of 118	3 of 30	11 of 66	26 of 145	353	170	121
POS Summative score								
Mean		15.9		8.04		9.81	10.74	11.4
Median POS						9	10	11
POS Range		3-31				0-27	1-27	0-27
Pain								
Median			2			1	1	2
Mean				1.41		1.28	1.33	1.68
Percentage severe-overwhelming	39	57	43.3		24.3	17	20	27.3
Other symptoms								
Median			2			0	0	1
Mean				1.1		0.65	0.63	1
Percentage severe-overwhelming	33.3	30	4.2		27.2	6.8	7.1	10.7
Personal Anxiety								
Median			2			1	2	2
Mean				0.8		1.63	1.93	1.79
Percentage severe-overwhelming	39.7	55	43.3		23.6	25.8	34.7	29.8
Family anxiety								
Median			3			2	3	3
Mean				1.56		2.17	2.63	2.4
Percentage severe-overwhelming	62.3	79	56.6		49.6	45.9	59.4	38.8
Information needs								
Median			0			0	0	0
Mean				0.09		0.72	0.6	0.72
Percentage severe-overwhelming	11.7	8	3.3		12.6	8.8	4.1	9.9
Ability to share								
Median			0			0	0	0
Mean				0.85		0.75	0.75	1.23
Percentage severe-overwhelming	10.4	11	6.7		10.4	10.2	11.2	13.2
Life-worth								
Median			1			0	0	0
Mean				0.64		0.55	0.55	1.05
Percentage severe-overwhelming	15.8	43	16.7		13.6	4.2	5.3	9.9
Self-worth								
Median			1			1	1	1
Mean				1.09		1.2	1.29	1.63
Percentage severe-overwhelming	26.3	31	16.7		15.9	13.6	15.9	27.3
Time use								
Median			0			0	0	0
Mean				0.07		0.14	0.15	0.16
Percentage severe-overwhelming	31.6	3	10		5.9	3.4	3.5	3.3
Practical issues								
Median			0			0	0	0
Mean				0.43		0.52	0.66	0.68
Percentage severe-overwhelming	10.5	9	6.7		7.8	1.7	8.8	4.1

Table 41: Previously published data for POS items and summative scores, as well as the current study's data.

A wide range of summative POS scores and item scores have previously been reported (Table 41). No previous study has reported POS responses from lung cancer patients only; however, the figures reported and the responses patterns are similar to previous work. The current study has a relatively low prevalence of reported severe to overwhelming pain. This may reflect that the patients are in the out-patient setting of a lung cancer clinic rather than within a palliative care service. The figures from the current study are percentages including missing values and most of the other studies quoted exclude missing values. It is of particular note that, in each study, anxiety perceived in the support network is the highest-rated problem no matter which descriptive statistic is used.

The reported impact on patients' lives of most items measured by POS appears to be relatively low when assessed by median response. However, median values for each item do not evaluate the specific prevalence of moderate to overwhelming symptoms. Three items from POS (anxiety perceived in support network, personal anxiety and pain) had a median value equal to or greater than two (moderate) in each of the different groupings studied. In addition to those three, dyspnoea was also rated as troubling in the respiratory questions (median 2 in all groupings). Previous reports within the literature regarding POS scores were mainly related to validation of the tool. However, the Stevens et al[218] descriptive study of patients with advanced cancer (on admission to a hospital based palliative care unit) also found apparently low levels of baseline supportive care needs measured by median POS values. Of the 30 patients studied by Stevens et al,[218], six out of ten issues had a median value of 0 or 1, with four main areas scoring higher: patients' perception of family anxiety (median 3), personal anxiety (median 2), pain (median 2) and 'other' symptoms (median 2). Again, both family and personal anxiety were rated the highest in this study. Higginson[215] explored the factors contributing to an overall POS score in a heterogeneous population and found that four main factors explained 67% of the variability of POS scores – life-worth combined with self-worth, information needs, family anxiety and pain combined with other symptoms. This study[215] also evaluated two other patient-reported outcome measures.

Despite the use of an adapted version of POS within the LCQ, the pattern of responses and levels of symptoms identified would suggest the questions retained face, content and construct validity. However, this was not formally assessed and therefore remains speculative. The palliative outcome questions within the LCQ also retained internal

consistency with a Cronbach's alpha value of 0.79 (This compares to 0.65 reported during POS development[147]). Validation and development of the LCQ was beyond the scope and resources of the current project. The lack of formal validation limits the conclusions that can be drawn.

6.3.3 Physical Symptoms and Function

Pain is a key symptom in the lung cancer population (see Sections 5 and 6.2). An overall clinic prevalence of 40.8% of pain, that is either moderate (23.8%) or severe-overwhelming (17%), is in keeping with the high symptom burden expected within the lung cancer population. The prevalence of pain in patients with lung cancer ranges from 20-86% depending on the phase of illness evaluated (Table 11 to Table 15). In this study, 42.9% of newly diagnosed patients rated pain as moderate, severe or overwhelming. The pain burden within the last three months of life was significantly higher than in the general clinic population. Pain has been reported to be an adverse prognostic indicator in advanced cancer in previous studies.[135, 337]

Although POS records the presence and severity of pain, it does not explore location or cause. However, from a supportive care perspective, the main issue is to identify the existence of the problem, to further elucidate the details and to establish subsequent management clinically. The high prevalence of pain in lung cancer patients attending for routine review, new patients' appointments and near end of life in lung cancer is confirmed here and should be considered as part of the clinical assessment on each review.

'Other' symptoms did not rate highly in any of the groupings in this study. Overall in the clinic, 6.8% of patients rated 'other' symptoms as severe or overwhelming. This is in contrast to most previously published studies (Table 41). However, it should be noted that the response in the 'other' symptoms section cannot be related directly to previous studies using only POS without any additional questions. The LCQ asks patients to rate the effects of dyspnoea, cough and haemoptysis in addition to the symptom of pain. As such, these additional symptoms are less likely to be rated as 'other' symptoms. The fact that Higginson reported dyspnoea as the most frequently cited symptom in the free text of 'other' symptoms in version 1 of POS reinforces this postulate.[147]

The presence of at least one respiratory symptom was observed in over 90% of patients, irrespective of phase of illness. Median respiratory summary scores (possible score = 0-12) were similar for all patient groupings, although in the last three months of life higher scores were observed (median 4). In every group, the respiratory symptoms were ranked the same by median scores: dyspnoea (median 2), cough (median 1) and haemoptysis (median 0).

Low levels of haemoptysis are in keeping with previous findings regarding lung cancer symptoms throughout the cancer journey (Section 5). Overall, 89% of patients had no or slight problems with haemoptysis, and only 5.7% rated this symptom as moderate-overwhelming. Slightly more patients rated this symptom as moderate-overwhelming in the last three months of life (5.8%) and within six weeks of diagnosis (8.8%). Despite the low levels of haemoptysis in this population, it remains a cardinal symptom of diagnostic importance (often a presenting symptom)[83, 86] and can generate great anxiety and fear for patients.[338]

Moderate to overwhelming cough was present in 34.5% of the general clinic population and 35.3% of the newly diagnosed patients; it increased in prevalence in the last three months of life (57.1%). However, comparison of median scores did not show a significant difference in cough in any phase of illness compared to the general study population. Cough has not been identified as an adverse prognostic indicator in lung cancer, and its utility in diagnosis is reduced by low specificity.[82]

Dyspnoea was identified as the most troublesome respiratory symptom in this study; it was present in over 80% of all patients irrespective of phase of illness, and the prevalence of moderate to overwhelming dyspnoea in the general study population was 49.8%, in newly diagnosed patients 49.4% and in patients who died within three months of LCQ completion 62%. Furthermore, in the free text sections of the LCQ indicating 'main issues', dyspnoea was the most frequently rated of all the responses in each grouping (Table 37). Dyspnoea, again, was most frequently rated as a reason for visiting the general practioner between clinic appointments (with the exception of collecting prescriptions; Table 38). This is in keeping with previous studies looking at the prevalence of breathlessness in lung cancer patients utilising a variety of assessment tools (Section 1.5.2).

Comparison of median scores showed a significant increase in dyspnoea in patients who died than in the general study population ($p<0.01$) and in patients in the last three months of life ($p=0.02$). There was no difference between dyspnoea reported by the general study population and dyspnoea reported by newly diagnosed patients (Table 39). Dyspnoea has been previously identified as an adverse prognostic indicator in advanced cancer and within lung cancer.[135, 337, 339] Increased symptom frequency and severity in lung cancer patients in the last three months of life has been reported by Lutz et al.[297]

Poor performance status is a well defined adverse prognostic indicator in lung cancer (see Section 1.4.5). In this study, patient-rated performance status was significantly poorer in those who died within three months of completing the LCQ. This will be explored further in Section 8.

6.3.4 Psycho-Emotional Issues

Psychosocial distress may occur in 10-40% of cancer patients.[340, 341] In a study of 96 newly diagnosed patients, Steinberg et al[160] reported a prevalence of clinically significant distress in 51% of patients and also high levels of depression and/or nervousness in 26.5% of patients. Montazeri et al[342] found post diagnosis levels of depression were significantly greater than pre-diagnosis levels in lung cancer patients. POS considers several aspects of personal psycho-emotional distress in three specific questions: 'have you felt anxious or worried about your illness or treatment?', 'have you felt life was worthwhile?' and 'have you felt good about yourself?' The question 'have any of your friends or family been worried about your illness or treatment?' evaluates the patients' perception of how much worry is present in the support network. A final question 'have you been able to share about how you are feeling with family or friends?' evaluates the degree of support perceived to be available to the patients from that support network. In this study, we found high levels of moderate to overwhelming personal anxiety within the overall clinic population (45.6%), and a prevalence of moderate to overwhelming reduced self-esteem of 29.5%, as assessed by the question 'have you felt good about yourself?'. An overall prevalence of reduced life-worth of 12.1% was identified.

The median level of anxiety perceived in the support network (median 2) shows this as the highest-rated concern within the POS responses. Personal anxiety was also highly

rated (median 1). In all other studies of cancer patients using POS, this has been a common finding. There have been no studies to confirm that patients' perception of worry and anxiety amongst friends and family truly reflects reality; however, in studies utilising concurrent staff POS questionnaires, there is concordance. The finding that lung cancer patients are concerned about the worries of their support network has also been identified by Li and Girgis.[157] In their study of 888 patients with a variety of cancers, the authors reported that those with lung cancer had significantly more unmet supportive care needs than those with other cancers. Furthermore, the main reported increased needs were in the psychological and daily living domains of the evaluation tool. It is of interest that lung cancer patients rated 'concerns about the worries of those close to you' as the most frequent unmet psychological need (53.4%), followed by 'fears about the cancer spreading' (52%) and 'fears about physical disability or deterioration' (49.5%). In contrast, these three psychological concerns were rated in reverse order and at lower frequencies by patients with other cancers: 'fears about physical disability or deterioration' (36.6%), 'fears about the cancer spreading' (36.1%) and 'concerns about the worries of those close to you' (33%).[157]

The majority of patients (72.8%) in the clinic were able to share how they were feeling with family or friends, but 21.2% were only able to share 'sometimes' (11%) or 'occasionally' to 'not at all' (10.2%). Within the group of 91 patients experiencing high anxiety (severe-overwhelming), 11% were only able to share their feelings occasionally or not at all. Of the 15 patients who felt life was worthwhile 'occasionally or not at all', three (20%) were not able to share feelings. In this minority of patients with high psychosocial distress and high social isolation, targeted supportive care may benefit overall care goals and reduce symptom burden. Psycho-emotional aspects are further explored in Section 9.

6.3.5 Information Needs and Practical Aspects of Care

Information needs within the lung cancer population may be high, with many patients desiring information to be consistent, individualised and actively offered.[12, 343] Meredith et al[344] found that 79% of cancer patients in the West of Scotland (n=269) wanted 'as much information as possible'. Krishnasamy et al[13] reported that although many lung cancer patients 'feel able' to ask questions at time of diagnosis in out-patients settings (34%), some did not wish to or felt too upset to ask questions. A recent audit of information needs in Glasgow showed that up to 91% of patients gain their main

information from the doctor.[345] Within the Stobhill general clinic population, 64.3% of patients felt they had been given full information (although sometimes hard to understand); a further 14.4% gained information on request but still wished more; 16.1% stated that they gained little or no information despite wanting to know more. It may be that some of those who wished more information did not actively seek it or felt they should not seek it in the clinic setting.[14] Of these 57 patients receiving little or no information, four (7%) also reported they were able to share how they were feeling with no one or only occasionally. Over one third of the patients attending the lung cancer clinic had unmet information needs. This is particularly important for a hospital-based service, as Edmonds et al[178] reported lung cancer patients were significantly more likely than those with chronic lung disease to ask for information from a hospital doctor.

Lung cancer patients may also have practical matters that require support as a result of the cancer or due to other factors. In this study, only 1.7% (6) of clinic patients reported having any unaddressed practical matters.

6.3.6 Satisfaction

The majority of respondents were satisfied or very satisfied overall with investigations, with the way diagnosis was delivered and with follow-up (Figure 12B). No difference was observed between each of the groupings in median scores for either investigations or follow-up (median 0 for all). A significantly higher median of 1 was observed for satisfaction in the 'way diagnosis was given' in the groupings of patients who died within three months of completing QF compared to the general clinic population. This may relate to overall distress as a patient nears the end of life. However, it is of note that very few patients expressed dissatisfaction with any of the areas assessed.

As discussed in Section 3 there are many issues that surround the measurement of satisfaction that limit the scope of conclusions. Satisfaction evaluation has evolved from consumer survey models within the private sector and may have been driven through public policy rather than stemmed from patients' agenda.[232, 238, 346] The importance of patient satisfaction and it's potential relevance to the quality agenda has been recognised.[235, 236, 240, 241, 265, 347] However, issues including a lack of accepted definition,[346] a poor understanding its theoretical basis,[237, 238] heterogeneity in evaluation methodologies and an apparent bias towards reporting high levels of satisfaction requires satisfaction surveys to be considered at most exploratory.[236] Gill

and White[238] summarise some possible theoretical models for underpinning satisfaction evaluations. One definition that has been offered states satisfaction is ‘a recipient's reaction to salient aspects of the context, process and result of the service experience'. The reaction can be considered in cognitive, emotional and affective terms.[236] In an effort to address the bias that may result from patients not wishing to criticise a service the ‘discrepancy model’ places value on responses that indicate dissatisfaction. [242].[241] The major component of these theories link satisfaction to achieving previous expectations in a way that ties with patients’ own beliefs, personal approaches and views of quality.

Recognising these limitations, it is interesting to observe that there were high levels of satisfaction reported in this study. This is in keeping with a previous study in the Stobhill clinic[231] and in Williamson et al’s[265] audit of satisfaction with nurse-led lung cancer follow-up. Viewed from a sceptical point of view this may only reflect the bias of against providing critical responses described above. Viewed at face value, these responses could represent the reporting of high satisfaction with service (irrespective of the reasons for why this assessment is being made).Viewed from a discrepancy model, the lack of dissatisfaction may serve to affirm that patients are accepting of the current level of service in Stobhill. Furthermore, from the discrepancy viewpoint that there was a significantly lower level of satisfaction in patients who died within 3 months may be of great importance. This area would need further study and may require the taxonomy of satisfaction research to be further defined before any such research is possible. It has been argued that satisfaction research is a waste of time. In the context of improving quality and involving service users, it is likely that an increased understanding of the relationships between quality, expectation and satisfaction will be beneficial to service provision.

6.3.7 Service Use and Preferences

Some patients may feel that their time is being used inefficiently through clinic attendances and waiting room times.[343] In this clinic population, 81.3% of patients felt no time had been wasted, 6.3% up to half a day and only 3.4% more than half a day. There was little change in these ratings throughout the phases of the lung cancer journey. These findings are in keeping with the views expressed regarding how many health care professionals are involved in care. Most patients did not feel they were ‘seeing too many healthcare professionals’ in any of the groupings.

Attendance at the patient's general practitioner (GP) between clinic appointments varied. This question was asked in the LCQ after the first 12 months. The majority (though not statistically significant) of respondents from the general clinic population had not seen their GP between visits (Figure 12A). This was also the case for newly diagnosed patients (Figure 14A). However, a significant majority of patients who completed a LCQ in the last three months of life had attended their GP (Figure 16A). This may relate to the finding that there was an increase in new or changing symptoms since the last review reported in the patients who died within three months of LCQ completion compared to both the general clinic and newly diagnosed patients (see Figure 12A, Figure 14A and Figure 16A). It is of interest to note that the main reasons for attending the GP in the final three months of life were recorded in the free text sections as dyspnoea and pain (Table 38). This may represent an increasing symptom burden in the advanced stages of lung cancer and, therefore, an increased usage of community health care services. Edmonds et al[178] found that in the final year of life, the majority of lung cancer patients attended their GP ten or more times, and 53% of lung cancer patients were seen by their GP within the last seven days of life. In addition, 74% of lung cancer patients felt the GP care was excellent or good, but only 60% of relatives felt the GP's understanding of the deceased's problems was good.

The BTS guidelines for organisation of care for patients with lung cancer state that the patient should be aware of who is in charge of their care.[69] In this study there was a wide variation in who the patient regarded as the lead healthcare professional. Some of this variation may reflect the different phases of the lung cancer journey and/or the strength of relationship between the patient and GP. However, at least 10% of patients in each grouping documented that they were 'uncertain' of who was in charge. This finding may have implications in these patients seeking help at the optimal time.

The analysis of documented referrals showed that around half the patients in the last three months of life had been referred to palliative care. This is a lower than expected referral rate, but it should be noted that only documented referrals were identified. As such, telephone referrals were not identified in this study. Only around 20% of the general clinic and 20% of newly diagnosed patients had documented palliative care referrals (see Figure 12B, Figure 14B and Figure 16B). This is likely to reflect clinical practice of referring when it is felt the end of life is approaching. However, given the

short survival of many lung cancer patients from point of diagnosis, it may be that earlier referral to palliative care would be appropriate.

The role of routine follow-up appointments is not well evidence-based. It is also unclear when and if routine imaging should be used in follow-up. There is little evidence regarding patients' own views about follow-up (see Section 4.3) We found that the majority of patients wished to continue with routine MDT clinic review appointments compared to GP follow-up or nurse specialist follow-up (see Figure 12B, Figure 14B and Figure 16B). There was, however, an increase in the number of patients preferring GP-led follow-up in those who died within three months of LCQ completion with less preferring nurse-led follow-up. Cox et al[267] evaluated this issue in more detail, reporting that standard or nurse-led follow-up was preferred to GP-led follow-up by selected lung cancer patients of PS<2 with no active medical issues. However, patients also describe the need to access medical advice when appropriate. Cox et al[267] concluded that around 20% of the lung cancer clinic population studied could be eligible and accepting of nurse-led follow-up. Moore et al[264, 270, 271, 348] also described the acceptability and effectiveness of nurse-led follow-up (see Section 4.3). Only 17% of patients receiving nurse-led follow-up would have preferred to return to medical only follow-up if forced to choose. Stent[273] reported that four out of five patients undertaking qualitative interviews regarding follow-up wished hospital-based care to continue rather than being discharged to the care of the their GP. In a recent article, Krishnasamy et al[272] surveyed 30 lung cancer patients at a single treatment centre regarding follow-up preferences. They found that most patients expected to be seen for follow-up within two weeks of any treatment, and that the majority (75%) strongly agreed they would like follow-up by a 'cancer specialist' with few wishing follow-up by GP or specialist nurse. However, when alternative modes of follow-up (GP or nurse) were co-ordinated with a defined route of returning to a 'cancer specialist' if necessary, more patients strongly agreed with these options (48% and 41%, respectively).

6.4 Conclusions

Lung cancer patients face a disease of high symptom burden from diagnosis, including physical and psychosocial issues. This study of lung cancer patients attending the Stobhill lung cancer clinic demonstrates that despite current service provision there remains unmet need in this population. The three main issues identified were: anxiety, pain and dyspnoea. These three key issues are evaluated further in Sections 9-11.

Anxiety is a major issue for lung cancer patients from diagnosis throughout their lung cancer journey. In keeping with previous reports, lung cancer patients perceive that their support network is highly anxious throughout the cancer journey. Furthermore, lung cancer patients also report high levels of personal anxiety. Low self-esteem and reduced sense of life-worth is present in a few patients and is of particular concern for those who describe little access support through sharing their worries or anxieties.

Performance status is reduced as lung cancer advances, and many lung cancer patients have significantly reduced physical function. However, practical aspects of patient care are well addressed, but there is a lack of information for a large percentage of patients. Most patients are satisfied with the service they are receiving. However, the lower satisfaction reported nearer the end of life merits further exploration but this may be limited by the available methodologies for satisfaction research.

Most patients are also satisfied with the current follow-up structure. However, this is designed to mainly address bio-physical aspects of care and may not fully address potentially important psychosocial issues. Earlier and more frequent referral to palliative care services may be appropriate. Nurse-led services may also be acceptable and could aid in assessment and management of supportive care issues. However, many patients prefer routine medical reviews. The LCQ appears to allow the identification of these issues and could potentially be used to monitor the success of interventions established to address them. This demonstrates the validity of systemic assessment of supportive care issues within a clinical service. The approach to this could be strengthened by utilising fully validated instruments targeted towards the key issues. It would be important to avoid instrument burden and to identify tools that could function in a busy clinical service. Utilising a screening tool with a broad range of questions, such as POS may allow this balance to be struck. More detailed tools could be used when individual issues are identified.

7 Predictors of Supportive Care Needs in Lung Cancer

In keeping with Aim 4a, this section reports an evaluation of possible predictors of supportive care needs as measured by POS. The predictors evaluated were all readily available within the Stobhill clinical service and may serve to allow effective and efficient targeting of supportive care within the service. The methods and statistical approach are outlined in Section 3.

7.1 Introduction

'Supportive care' can be defined as:

> *Care that helps the patient and their family to cope with cancer and the treatment of it – from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps maximise the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment.*[141]

Providing supportive care is now considered to be part of good management of lung cancer.[10, 139] Furthermore, 'best supportive care' is a term now often utilised to describe the default or standard arm of many clinical trials within the oncology setting[140] (Section 1.4.7). Despite this, patients with lung cancer continue to have unrecognised supportive care needs (Section 6.2). Hill et al[11] described the experience of 89 patients with lung cancer at diagnosis who were treated by a health care team focusing only on physical symptoms; none of the patients' psychosocial or emotion concerns were addressed. There is some evidence that systematic assessment of symptoms and unmet needs can aid the identification and management of these issues.[264, 270, 276] Sanders et al[216] confirmed that the majority of lung cancer patients do wish supportive care needs to be addressed and are willing to take up offers of support and appropriate referrals to supportive care services. Identification of unmet needs and subsequent referrals may be enhanced by focusing attention on those found to be most in need. In a multivariate study of 109 lung cancer patients, Sanders et al[216] described poorer physical function, increased symptom burden, problem-focused coping and low satisfaction with health care as the four independent factors associated with higher levels of supportive care needs. The current study utilised POS to assess supportive care needs and evaluated predictors of higher needs in three groupings: all patients attending the lung cancer

clinic, newly diagnosed patients and patients within the last three months of life when they complete the LCQ.

7.2 Results

7.2.1 Supportive Care Needs in All Patients Attending the Lung Cancer Clinic

A total of 303 (85.5%) patients completed all the POS questions allowing a summary score to be calculated. The factors tabulated below were evaluated for significant differences across lower and higher supportive care needs (Table 42). The factors identified as significant were: age, TNM stage of lung cancer in NSCLC (but not in SCLC), performance status rated by patients during LCQ completion, PS rated by a doctor at diagnosis, treatment type delivered, respiratory symptom score and frequency of review.

There were no significant differences found for gender, presence of metastases (comparison of TNM stage 4/extensive stage SCLC to all other stages), histological types, time from diagnosis, deprivation level, satisfaction score and attendance at the patient's GP between lung cancer clinic appointments.

	POS <10		POS ≥ 10					
Factor	Number	Percentage	Number	Percentage	χ^2	Df	p value	Significant
Gender								
Male	87	58.8	61	41.2				
Female	78	50.3	77	49.7	2.19	1.00	0.166	
Age								
<65 years	43	45.7	51	54.3				
≥65 years	122	58.4	87	41.6	4.17	1.00	0.046	*
Histology								
Clinical	28	51.9	26	48.1				
NSCLC	116	55.2	94	44.8				
SCLC	21	53.8	18	46.2	0.21	2.00	0.902	
Stage NSCLC and clinicoradiological								
1A	15	68.2	7	31.8				
1B	33	76.7	10	23.3				
2A	6	31.6	13	68.4				
2B	7	50.0	7	50.0				
3A	13	52.0	12	48.0				
3B	33	50.0	33	50.0				
4	34	48.6	36	51.4	15.97	6.00	0.014	*
Stage SCLC								
Limited	8	61.5	5	38.5				
Extensive	12	48.0	13	52.0	0.63	1.00	0.428	
Presence or absence of metastases								
None	119	57.2	89	42.8				
Metasases	46	48.4	49	51.6	2.03	1.00	0.172	
Time from diagnosis to POS								
Within 3 weeks	50	47.6	55	52.4				
3-6 weeks	22	52.4	20	47.6				
6 weeks to 3 months	17	58.6	12	41.4				
3-6 months	20	57.1	15	42.9				
6-12 months	19	54.3	16	45.7				
> 12 months	35	63.6	20	36.4	4.21	5.00	0.520	
Performance status rated by patients								
0-1	120	74.1	42	25.9				
2	24	40.0	36	60.0				
3-4	21	25.9	60	74.1	56.78	2.00	<0.001	**
Diagnosis PS, assessed by doctor								
0-1	120	62.8	71	37.2				
2	29	40.8	42	59.2				
3-4	1	16.7	5	83.3	56.78	6.00	0.001	**
Treatment delivered								
Surgery	37	67.3	18	32.7				
Radical Radiotherapy	11	50.0	11	50.0				
Palliative Radiotherapy	33	41.8	46	58.2				
Chemotherapy	41	56.9	31	43.1				
Supportive Care	21	53.8	18	46.2				
Combined	7	87.5	1	12.5	12.65	5.00	0.027	*
Deprivation								
Dep Cat 1-5	81	57.9	59	42.1				
Dep cat 6 or 7	83	52.2	76	47.8	0.96	1.00	0.353	
Respiratory Score								
0-4	151	62.7	90	37.3		Mann Whitney U		
5-8	12	21.1	45	78.9		two tailed test		
9-12	1	33.3	2	66.7	na		<0.001	***
Satisfaction score								
0-4	63	55.8	50	44.2		Mann Whitney U		
5-8	0	.0	3	100.0		two tailed test		
9-12	0	.0	0	.0	na		0.852	
Last Clinic appointment								
1st Appointment	34	44.7	42	55.3				
<4 weeks	52	51.5	49	48.5				
4-8 weeks	20	48.8	21	51.2				
2-4 months	22	62.9	13	37.1				
>4 months	35	76.1	11	23.9	13.46	4.00	0.009	***
GP attendance between clinics								
No	39	60.0	26	40.0				
Yes	26	41.9	36	58.1	4.14	1.00	0.051	

Table 42: All patients attending the lung cancer clinic. Univariate analysis of factors across groups of higher and lower supportive care needs as measured by POS. Percentages adjusted for missing data. *p<0.05, **p<0.01 and ***p<0.001

Significant factors were entered into a backwards logistic regression model to test for independent effects. Frequency of review was not entered as this was likely to be related to ongoing active issues rather than a useful predictor of increased supportive care needs. Thus, the following factors were added to the model: patients-rated PS, doctor-rated PS at diagnosis, age, respiratory score and treatment delivered. Treatment delivered was considered a dichotomous variable for active anti-cancer treatment or not. In addition to these significant variables, additional factors of interest (factors identified in previous studies) were included in the model: gender, presence of metastases and deprivation. Results are shown in Table 43.

							95% CI for Odds Ratios	
	b	SE	Wald	df	p value	Odds Ratio	Lower	Upper
Performance status 0-1			28.855	2	<0.001			
Performance status 2	1.383	.398	12.100	1	.001	3.99	1.83	8.70
Performance status 3-4	2.030	.398	26.031	1	<0.001	7.62	3.49	16.62
Respiratory score	-.989	.341	8.430	1	0.00	1.48	1.23	1.78
Age >65	.392	.094	17.228	1	<0.001	0.37	0.19	0.73
Constant	-1.567	.374	17.609	1	<0.001	0.21		

R^2=0.283 (Cox and Snell); 0.379 (Nagelkerke) Model X^2=82.97, df=4, p<0.001
Hosmer-Lemeshow test: X^2=11.38, df=8, p=0.181

Table 43: Independent factors associated with higher supportive care needs identified through backwards logistic regression for all patients.

A test of the full model against constant only model was statistically significant (model X^2=82.97, df=4, p<0.001). Nagelkerke's R^2 of 0.379 indicated that around 38% of variance was explained by the model. Overall prediction success was 74.7% (79.6% for POS<10 and 68.8% for POS>10). This compares to the null model overall prediction success of 55%. Each of the predictors in the final model was significant at the p<0.05 level. As such, higher levels of supportive care needs were independently associated with reduced performance status, higher respiratory symptom scores and a younger age. There were no significant effects from the other variables, which were excluded from the final model. For a fixed age and respiratory score, a patient with a PS of 3-4 is 7.62 (95% CI 3.49-16.62) times more likely to have higher supportive care needs (POS>10). For a fixed PS and age, each unit increase in respiratory score increases the likelihood of increased supportive care needs by 1.48 (95% CI 1.23-1.78) times.

Respiratory score was an independent predictor of higher supportive care needs. This was further examined to assess which variables making up the respiratory score were the significant factors. Dyspnoea, cough and haemoptysis were dichotomised into absent (0) or present (1) categories and entered into the original model instead of the

summated respiratory score. This identified cough and haemoptysis as significant factors but dyspnoea as non-significant (Table 44).

							95% CI for Odds Ratios	
	b	SE	Wald	df	p value	Odds Ratio	Lower	Upper
Performance status 0-1			44.48	2	<0.01			
Performance status 2	1.67	0.39	18.54	1	<0.01	5.31	2.48	11.34
Performance status 3-4	2.44	0.39	39.81	1	<0.01	11.42	5.36	24.35
Age >65	-0.95	0.34	7.81	1	0.01	0.39	0.20	0.75
Cough	0.97	0.40	6.05	1	0.01	2.65	1.22	5.76
Haemoptysis	0.85	0.44	3.74	1	0.05	2.34	0.99	5.56
Constant	-1.47	0.44	11.24	1	<0.01	0.23		

R^2=0.259 (Cox and Snell); 0.347 (Nagelkerke) Model X^2=74.68, df=5, p<0.001
Hosmer-Lemeshow test: X^2=2.58, df=8, p=0.958

Table 44: Independent factors associated with higher supportive care needs identified through backwards logistic regression using individual respiratory factors for all patients.

A test of the full model against constant only model was statistically significant (model X^2=74.68, df=5, p<0.001). Nagelkerke's R^2 of 0.347 indicated that around 35% of variance was explained by the model. Overall prediction success was 74.3% (74.5% for POS<10 and 74.3% for POS>10). This compares to the null model overall prediction success of 55%. Each of the predictors in the final model was significant at the p<0.05 level. As such, higher levels of supportive care needs were independently associated with reduced performance status, presence of cough, presence of haemoptysis and a younger age. There were no significant effects from the other variables, which were excluded from the final model (i.e. doctor-rated PS at diagnosis, active anti-cancer treatment, gender, deprivation, presence of metastases and dyspnoea).

Correlations between individual POS items and PS, respiratory score and age are tabulated below (Table 45).

POS items		Performance Status	Respiratory symptom score	Dyspnoea	Cough	Haemoptysis	Age
	Correlation Coefficient	.331**	.301**	.331**	.148**	.106	-.086
Pain	Sig. (2-tailed)	.000	.000	.000	.006	.053	.113
	N	331	332	340	336	332	341
	Correlation Coefficient	.386**	.386**	.341**	.294**	.158**	-.037
Other symptoms	Sig. (2-tailed)	.000	.000	.000	.000	.004	.506
	N	328	329	332	330	330	332
	Correlation Coefficient	.278**	.353**	.259**	.263**	.183**	-.240**
Personal anxiety	Sig. (2-tailed)	.000	.000	.000	.000	.001	.000
	N	331	330	334	332	331	334
	Correlation Coefficient	.279**	.298**	.242**	.255**	.102	-.160**
Family anxiety	Sig. (2-tailed)	.000	.000	.000	.000	.065	.003
	N	329	329	332	331	329	332
	Correlation Coefficient	.195**	.181**	.145**	.143**	.077	-.048
Ability to share	Sig. (2-tailed)	.000	.001		.009	.167	.379
	N	326	324	331	329	325	332
	Correlation Coefficient	.370**	.243**	.207**	.212**	.058	.005
Life worth	Sig. (2-tailed)	.000	.000	.000	.000	.306	.927
	N	314	314	320	317	315	320
	Correlation Coefficient	.549**	.459**	.406**	.329**	.170**	-.013
Self esteem	Sig. (2-tailed)	.000	.000	.000	.000	.002	.813
	N	319	318	324	322	319	325
	Correlation Coefficient	.168**	.212**	.180**	.211**	.021	-.043
Information	Sig. (2-tailed)	.003	.000	.002	.000	.713	.448
	N	303	302	308	306	303	309
	Correlation Coefficient	.250**	.150**	.096	.165**	.061	-.144*
Practical	Sig. (2-tailed)	.000	.009	.091	.004	.288	.010
	N	309	308	314	312	309	315
	Correlation Coefficient	.077	.078	.057	.061	-.046	.002
Time use	Sig. (2-tailed)	.175	.170	.309	.279	.413	.968
	N	314	312	320	317	313	321

**Correlation significant at 0.01 level, *Correlation significant at 0.05 level (2 tailed)

Table 45: Spearman Rho correlations for POS items and PS, respiratory symptoms and age (all Q1).

PS and respiratory symptoms were positively correlated with pain, 'other' symptoms, personal anxiety, perceived support network anxiety, ability to share, life-worth, self-esteem, information needs and practical concerns. In particular, dyspnoea and cough were correlated with all POS items except time use. Haemoptysis was only correlated with 'other' symptoms, personal anxiety and low self-esteem. Age was negatively correlated to personal anxiety, perceived support network anxiety and practical needs. None of the variables was correlated to time use.

7.2.2 Supportive Care Needs in Newly Diagnosed Patients

A total of 147 of 170 newly diagnosed patients (86.5%) completed all POS questions allowing a summary score to be calculated. The factors tabulated below were evaluated for significant differences across lower and higher supportive care needs (Table 46).

Factor	POS <10		POS ≥ 10		χ^2	Df	p value	Significant
	Number	Percentage	Number	Percentage				
Gender								
Male	39	54.2	33	45.8				
Female	33	44.0	42	56.0	1.52	1	0.250	
Age								
≤50 years	0	.0	5	100.0				
51-69 years	30	44.8	37	55.2				
≥70 years	42	56.0	33	44.0	6.75	2	0.034	*
Histology								
Clinical	14	42.4	19	57.6				
NSCLC	48	52.2	44	47.8				
SCLC	10	45.5	12	54.5	1.05	2	0.591	
Stage NSCLC and clinicoradiological								
1A	3	42.9	4	57.1				
1B	17	77.3	5	22.7				
2A	13	38.2	21	61.8				
2B	3	60.0	2	40.0				
3A	16	55.2	13	44.8				
3B	26	51.0	25	49.0				
4	31	49.2	32	50.8	8.89	6	0.180	
Stage SCLC								
Limited	6	75.0	2	25.0				
Extensive	4	28.6	10	71.4	4.43	1	0.074	
Presence or absence of metastases								
None	49	54.4	41	45.6				
Metasases	23	40.4	34	59.6	2.77	1	0.127	
Time from diagnosis to POS								
Within 3 weeks	50	47.6	55	52.4				
3-6 weeks	22	52.4	20	47.6				
6 weeks to 3 months	0	.0	0	.0				
3-6 months	0	.0	0	.0				
6-12 months	0	.0	0	.0				
> 12 months	0	.0	0	.0	0.27	1	0.602	
Performance status rated by patients								
0	17	73.9	6	26.1				
1	35	64.8	19	35.2				
2	10	35.7	18	64.3				
3	8	25.8	23	74.2				
4	1	12.5	7	87.5	24.02	4	<0.001	**
Diagnosis PS, assessed by doctor								
0	3	37.5	5	62.5				
1	47	66.2	24	33.8				
2	15	34.9	28	65.1				
3	1	20.0	4	80.0	13.51	3	0.004	**
4								
Treatment delivered								
Surgery	5	55.6	4	44.4				
Radical Radiotherapy	4	44.4	5	55.6				
Palliative Radiotherapy	19	39.6	29	60.4				
Chemotherapy	20	54.1	17	45.9				
Supportive Care	11	52.4	10	47.6				
Combined	2	100.0	0	.0	4.47	5	0.483	
Deprivation								
Dep Cat 1-5	40	54.1	34	45.9				
Dep cat 6 or 7	32	45.1	39	54.9	1.17	1	0.320	
Respiratory Score								
0-4	63	55.8	50	44.2		Mann Whitney U		
5-8	7	22.6	24	77.4		two tailed test		
9-12	1	50.0	1	50.0	na		<0.001	***
Satisfaction score								
0-4	34	50.0	34	50.0		Mann Whitney U		
5-8	0	.0	2	100.0		two tailed test		
9-12	0	.0	0	.0	na		0.050	
GP attendance between clinics								
No	23	54.8	19	45.2				
Yes	12	33.3	24	66.7	3.60	1	0.070	

Table 46: Newly diagnosed patients. Univariate analysis of factors across groups of higher and lower supportive care needs as measured by POS. Percentages adjusted for missing data. *p<0.05, **p<0.01 and ***p<0.001

There were no significant differences found for gender, presence of metastases, histological types, stages, treatment delivered, time from diagnosis, deprivation level, satisfaction score and attendance at the patient's GP between lung cancer clinic appointments. The factors identified as significant were: age, performance status rated by patients during LCQ completion, PS rated by a doctor at diagnosis and respiratory symptom score. As in the previous section, the respiratory symptom variables were dichotomised and the model was repeated to assess the main factors (Table 47).

							95% CI for Odds Ratios	
	b	SE	Wald	df	p value	Odds Ratio	Lower	Upper
Performance status 0-1			19.18	2	<0.01			
Performance status 2	1.53	0.57	7.22	1	0.01	4.63	1.51	14.14
Performance status 3-4	2.22	0.54	16.97	1	<0.01	9.23	3.21	26.57
Age >65	-1.28	0.47	7.35	1	0.01	0.28	0.11	0.70
Constant	0.05	0.38	0.02	1	0.90	1.05		

R^2=0.212 (Cox and Snell); 0.282 (Nagelkerke) Model X^2=27.34, df=3, p<0.001
Hosmer-Lemeshow test: X^2=0.699, df=3, p=0.874

Table 47: Independent factors associated with higher supportive care needs identified through backwards logistic regression using individual respiratory factors for newly diagnosed patients.

A test of the full model against constant only model was statistically significant (model X^2=27.34, df=3, p<0.001). Nagelkerke's R^2 of 0.282 indicated that around 28% of variance was explained by the model. Overall prediction success was 68.7% (54.4% for POS<10 and 82.8% for POS>10). This compares to the null model overall prediction success of 50.4%. Each of the predictors in the final model was significant at the p<0.05 level. As such, higher levels of supportive care needs in newly diagnosed lung cancer patients were independently associated with reduced performance status and a younger age. For a fixed age, a patient with a PS of 3-4 is 9.23 (95% CI 3.21-26.57) times more likely to have higher supportive care needs (POS>10). There were no significant effects from the other variables which were excluded from the final model (i.e. doctor-rated PS at diagnosis, active anti-cancer treatment, deprivation, gender, presence of metastases, dyspnoea, cough and haemoptysis).

Correlations between individual POS items and PS, age and individual respiratory symptoms are tabulated below (Table 48).

POS items		Performance Status	Age	Dyspnoea	Cough	Haemoptysis
	Correlation	.403**	-.156*	.286**	.116	.140
Pain	Sig. (2-tailed)	.000	.045	.000	.139	.077
	N	160	166	166	163	161
	Correlation	.410**	-.088	.300**	.291**	.193*
Other symptoms	Sig. (2-tailed)	.000	.265	.000	.000	.014
	N	159	161	161	160	160
	Correlation	.214**	-.263**	.165*	.221**	.104
Personal anxiety	Sig. (2-tailed)	.007	.001	.036	.005	.189
	N	160	162	162	161	161
	Correlation	.179*	-.223**	.177*	.176*	.078
Family anxiety	Sig. (2-tailed)	.024	.004	.025	.025	.325
	N	159	161	161	161	160
	Correlation	.297**	-.054	.186*	.204*	.124
Ability to share	Sig. (2-tailed)	.000	.497	.018	.010	.122
	N	156	161	161	159	157
	Correlation	.353**	.009	.153	.263**	.095
Life worth	Sig. (2-tailed)	.000	.911	.057	.001	.246
	N	150	155	155	153	152
	Correlation	.498**	-.031	.334**	.257**	.165*
Self esteem	Sig. (2-tailed)	.000	.702	.000	.001	.040
	N	153	158	158	156	155
	Correlation	-.024	-.110	-.020	.135	-.033
Information	Sig. (2-tailed)	.772	.176	.807	.098	.691
	N	149	154	154	152	150
	Correlation	.288**	-.216**	.133	.234**	.009
Practical	Sig. (2-tailed)	.000	.007	.098	.004	.909
	N	150	155	155	153	152
	Correlation	.080	.047	.052	.013	.000
Time use	Sig. (2-tailed)	.329	.563	.522	.876	.998
	N	149	155	155	152	150

** Correlation significant at 0.01 level, *Correlation significant at 0.05 level (2 tailed)

Table 48: Spearman Rho correlations for POS items and PS and age (Q1<six weeks from diagnosis)

PS was positively correlated with pain, 'other' symptoms, personal anxiety, perceived support network anxiety, ability to share, life-worth, self-esteem, information needs and practical concerns. Age was negatively correlated to pain, personal anxiety, perceived support network anxiety and practical needs.

7.2.3 Supportive Care Needs in Patients in the Last Three Months of Life

A total of 109 of 121 patients (90.1%) in the last three months of life completed all the POS questions allowing a summary score to be calculated. The factors tabulated below were evaluated for significant differences across lower and higher supportive care needs (Table 49).

Factor	POS <10		POS ≥ 10		χ^2	Df	p value	Significant
	Number	Percentage	Number	Percentage				
Gender								
Male	24	40.0	36	60.0				
Female	19	38.8	30	61.2	0.02	1	0.896	
Age								
≤50 years	1	25.0	3	75.0				
51-69 years	15	31.9	32	68.1				
≥70 years	27	46.6	31	53.4	2.69	2	0.260	
Histology								
Clinical	7	46.7	8	53.3				
NSCLC	27	36.0	48	64.0				
SCLC	9	47.4	10	52.6	1.20	2	0.549	
Stage NSCLC and clinicoradiological								
1A	0	0.00	1.00	100.00				
1B	4	57.40	3.00	42.90				
2A	1	16.70	5.00	83.30				
2B	0	0.00	2.00	100.00				
3A	3	50.00	3.00	50.00				
3B	11	36.70	19.00	63.30				
4	14	37.80	23.00	62.20	4.49	6	0.611	
SCLC								
Limited	1	25.0	3	75.0				
Extensive	8	53.3	7	46.7	1.02	1	0.582	
Presence or absence of metastases								
None	21	36.8	36	63.2				
Metasases	22	42.3	30	57.7	0.34	1	0.560	
Time from diagnosis to POS								
Within 3 weeks	9	33.3	18	66.7				
3-6 weeks	1	20.0	4	80.0				
6 weeks to 3 months	7	38.9	11	61.1				
3-6 months	7	41.2	10	58.8				
6-12 months	9	37.5	15	62.5				
> 12 months	10	55.6	8	44.4	3.23	5	0.664	
Performance status rated by patients								
0	6	85.7	1	14.3				
1	13	54.2	11	45.8				
2	7	26.9	19	73.1				
3	13	32.5	27	67.5				
4	2	22.2	7	77.8	12.14	4	0.016	*
Performance status rated by doctor								
0	4	36.4	7	63.6				
1	22	46.8	25	53.2				
2	16	42.1	22	57.9				
3	0	.0	5	100.0				
4	42	41.6	59	58.4	4.22	3	0.239	
Treatment delivered								
Surgery	2	33.3	4	66.7				
Radical radiotherapy	0	.0	1	100.0				
Palliative radiotherapy	16	33.3	32	66.7				
Chemotherapy	11	47.8	12	52.2				
Supportive care	8	47.1	9	52.9				
Combined	1	50.0	1	50.0	2.68	5	0.749	
Deprivation								
Dep Cat 1-5	22	37.9	36	62.1				
Dep cat 6 or 7	21	41.2	30	58.8	0.12	1	0.729	
Respiratory Score								
0-4	38	52.8	34	47.2				
5-8	4	11.4	31	88.6				
9-12	0	.0	1	100.0	na		<0.001	***
Satisfaction score								
0-4	22	44.0	28	56.0		Mann Whitney U		
5-8	0	.0	1	100.0		two tailed test		
9-12	0	.0	0	.0	na		0.070	
Last clinic appointment								
1st appointment	6	31.6	13.0	68.4				
<4 weeks	12	41.4	17.0	58.6		Mann Whitney U		
4-8 weeks	13	39.4	20.0	60.6		two tailed test		
2-4 months	8	42.1	11.0	57.9				
>4 months	3	42.9	4.0	57.1	0.63	4	0.960	
GP attendance between clinics								
No	10	47.6	11	52.4				
Yes	13	36.1	23	63.9	0.73	1	0.393	

Table 49: Patients who died within three months of questionnaire completion. Univariate analysis of factors across groups of higher and lower supportive care needs as measured by POS. Percentages adjusted for missing data. *p<0.05, **p<0.01 and ***p<0.001

The only significant factors identified as significant were: patient-rated performance status and respiratory symptom score. As in the previous section, the respiratory symptom variables were dichotomised and the model was repeated to assess the main factors (Table 50).

							95% CI for Odds Ratios	
	b	SE	Wald	df	p value	Odds Ratio	Lower	Upper
Performance status 0-1			7.48	2	0.02			
Performance status 2	1.74	0.70	6.17	1	0.01	5.73	1.45	22.67
Performance Status 3-4	1.33	0.59	5.05	1	0.02	3.80	1.19	12.17
Dyspnoea	2.71	1.11	6.00	1	0.01	14.99	1.72	130.88
Haemoptysis	1.82	0.83	4.82	1	0.03	6.20	1.22	31.55
Constant	-3.32	1.16	8.22	1	0.00	0.04		

R^2=0.269 (Cox and Snell); 0.363 (Nagelkerke) Model X^2=28.14, df=4, p<0.001
Hosmer-Lemeshow test: X^2=1.025, df=5, p=0.960

Table 50: Independent factors associated with higher supportive care needs identified through backwards logistic regression using individual respiratory factors for patients who died within three months of questionnaire completion.

A test of the full model against constant only model was statistically significant (model X^2=28.14, df=4, p<0.001). Nagelkerke's R^2 of 0.363 indicated that around 36% of variance was explained by the model. Overall prediction success was 77.8% (61.1% for POS<10 and 88.9% for POS>10). This compares to the null model overall prediction success of 60%. Each of the predictors in the final model was significant at the p<0.05 level. As such, higher levels of supportive care needs in patients who died within three months of questionnaire completion were independently associated with presence of dyspnoea, reduced performance status and presence of haemoptysis. There were no significant effects from the other variables which were excluded from the final model, (doctor-rated PS, age, active anti-cancer treatment, deprivation, gender, presence of metastases and presence of cough). For a fixed performance status and symptomatic state of haemoptysis, patients with dyspnoea present are 14.99 (95% CI 1.72-130.88) times more likely to have higher supportive care needs (POS>10).

Correlations between individual POS items and respiratory symptoms are tabulated below.

POS items		Performance Status	Respiratory symptom score	Dyspnoea	Cough	Haemoptysis
Pain	Correlation Coefficient	.172	.307**	.339**	.144	.193*
	Sig. (2-tailed)	.070	.001	.000	.125	.040
	N	112	114	117	115	113
Other symptoms	Correlation Coefficient	.217*	.302**	.243**	.222*	.261**
	Sig. (2-tailed)	.022	.001	.009	.018	.005
	N	112	113	113	113	113
Personal anxiety	Correlation Coefficient	.199*	.305**	.317**	.215*	.138
	Sig. (2-tailed)	.035	.001	.001	.022	.145
	N	112	113	113	113	113
Family anxiety	Correlation Coefficient	.260**	.252**	.222*	.194*	.030
	Sig. (2-tailed)	.006	.007	.017	.039	.751
	N	112	114	114	113	113
Ability to share	Correlation Coefficient	.167	.190*	.126	.173	.164
	Sig. (2-tailed)	.080	.044	.178	.066	.084
	N	111	113	115	114	112
Life worth	Correlation Coefficient	.171	.284**	.262**	.253**	.259**
	Sig. (2-tailed)	.073	.002	.005	.007	.006
	N	110	112	114	113	111
Self esteem	Correlation Coefficient	.321**	.368**	.374**	.280**	.144
	Sig. (2-tailed)	.001	.000	.000	.003	.130
	N	111	113	115	114	112
Information	Correlation Coefficient	.103	.386**	.249**	.393**	.120
	Sig. (2-tailed)	.286	.000	.008	.000	.209
	N	110	112	114	113	111
Practical	Correlation Coefficient	.140	.143	.076	.133	.095
	Sig. (2-tailed)	.145	.133	.423	.160	.322
	N	110	112	114	113	111
Time wasted	Correlation Coefficient	.147	.267**	.164	.143	.231*
	Sig. (2-tailed)	.126	.004	.079	.130	.015
	N	110	112	115	113	111

** Correlation significant at 0.01 level, *Correlation significant at 0.05 level (2 tailed)

Table 51: Spearman Rho correlations for POS items and PS and age (QF<three months from death).

PS was positively correlated with 'other' symptoms, personal anxiety, perceived support network anxiety and self-esteem. Respiratory symptoms were negatively correlated to pain, personal anxiety, perceived support network anxiety, ability to share, life-worth, self-esteem, information needs, practical needs and time use. Dyspnoea was correlated with all items except practical issues and time use. Cough was correlated with 'other' symptoms, personal anxiety, perceived support network anxiety, life-worth, self-esteem and information needs. Haemoptysis was correlated to pain, 'other' symptoms, life-worth and time wasted.

7.3 Discussion

The potential predictors of increased supportive care needs in lung cancer patients remain poorly understood. The situation is complicated by the use of different assessment tools, outcome measures (e.g. distress, symptom distress, quality of life or supportive care needs) and methodologies. The only previous study to look directly at predictors of supportive care needs of lung cancer patients found higher levels of need associated with worse physical functioning (measured using a ten question subscale

from the SF-36), greater symptom burden and lower satisfaction with health care.[216] Sanders et al[216] reported that age, gender, marital status, time from diagnosis and cancer stage were not associated with supportive care needs.

In the current study, the key clinical variable that allows identification of patients with higher supportive care needs is PS. Increased PS was a significant predictor of higher supportive care needs in all three clinical groups. Respiratory symptoms were also significantly associated with higher supportive care needs: in particular, cough and haemoptysis in the general clinic population and dyspnoea and haemoptysis in the last three months of life.

Those who were younger (<65 years) had increased supportive care needs in both the general study population and in newly diagnosed patients but not when evaluated within the last three months of life. There was no significant association found for other factors in any of the clinical groups including gender, presence of metastases, histology, time from diagnosis, deprivation or active anti-cancer treatments.

7.3.1 Performance Status

Performance status is a global assessment of a patient's ability for self-care and ambulation. The use of functional assessment to aid management of cancer patients was first developed in 1948 by David Karnofsky.[314] The use of ECOG PS in elderly patients has been reported to overestimate function and may be less sensitive more in-depth functional assessment tools.[226, 228] A reduced function measured by ECOG PS has been used to aid clinical decisions, for research stratification, prognostication and as a predictor of increased symptom burden.[103] Furthermore, its use in lung cancer has been well validated over many years.[10]

Ferreira et al[323] utilised several symptom assessment tools, the EORTC cancer quality of life score and doctor-rated Karnofsky performance status assessment to evaluate the relationship between symptoms and PS in cancer patients. They found that a high symptom burden was independently associated with lower performance status (odds ratio 4.1, 95% CI 1.77-8.66, p=0.001) when controlled for gender, presence of metastases and hormone therapy. Ferreira et al[323] also reported that gender had no independent effect but the presence of metastases was associated with reduced PS. Presence and severity of pain in cancer patients has been correlated with reduced PS.

Martins et al[113] also reported an inverse relationship between symptom distress and physical function measured by Karnofsky PS. In their study of lung cancer patients, Martins et al[113] reported that increased global symptom distress (measured by the lung cancer symptom scale) was predicted by reduced PS independent of age, histology or clinical stage. Snyder et al[349] utilised the supportive care needs survey (SCNS) and EORTC-QLQ-C30 to assess concordance between cancer patients' supportive care needs, physical function and symptoms. They reported that patients with high function usually have low symptoms and low supportive care needs. When function is reduced there is an increase in symptoms, but this is not always perceived by the patient or reported by the patient as a 'need'. Kurtz et al[111] reported that reduced physical function in lung cancer patients (>65 years) was independently related to increased symptom severity, prior physical function and age (younger patients had greater loss of function). It was noted that older patients were more likely to have increased co-morbidities and reduced function at diagnosis than younger patients. There was no relationship between function and gender, stage or treatment delivered. Ostlund et al[172] assessed global quality of life in lung cancer patients and reported emotional functioning and fatigue to be independent predictors of reduced QOL but physical functioning was not a significant factor. However, there did appear to be a relationship between fatigue and physical function that made interpretation of the regression model difficult. Skaug et al[303] undertook multivariate analyses of 247 lung cancer patients in the last two months of life. They reported that initial PS was not a significant predictor of terminal symptoms. In the current study, patient-rated performance status within three months of death was an independent predictor of higher supportive care needs. Sanders et al[216] evaluated predictors of higher supportive care needs in lung cancer patients and found that physical function was a strong independent factor. Physical function was assessed by a subscale from the medical outcomes study short form. This ten item subscale assesses the impact of health on a patient's functional ability and activities of daily living. Better physical function was negatively correlated with total supportive care needs, physical and daily living needs, health system and information needs, patient care support needs and psychological needs.[324]

The finding that reduced physical function is associated with higher supportive care needs was confirmed in the current study. In those patients in whom ECOG PS is 3 or 4, the likelihood of having higher supportive care needs is 11 times compared to PS 0 or 1 patients. In newly diagnosed patients the increased likelihood is around nine times. In

the last three months of life the increased likelihood of higher supportive care needs for PS 3 or 4 was around four. For patients reporting PS of 2 in the last three months of life, there was a higher likelihood of around six times that of PS 0 or 1.

In the general population and in newly diagnosed patients, PS was not only a predictor of global higher supportive care needs, but reduced physical function was significantly correlated with each individual POS item with the exception of time use. In the last three months of life, PS was correlated with 'other' symptoms, personal anxiety, perceived anxiety in the support network and self-esteem but no other POS item. It is not clear why there is a difference amongst the clinical groups, but it is possible that in the last three months of life patients with advancing disease and reduced PS were less able to attend an out-patient review. As such, some patients with higher supportive care needs and PS of 3 or 4 may have been underrepresented in the sample. It is interesting to note this easily assessed, widely used clinical variable could aid targeting of supportive care within the lung cancer clinic. PS is used within the multidisciplinary setting to aid decisions about fitness for treatment. This may be the key time to identify patients in whom a more detailed evaluation of supportive care needs would be appropriate.

7.3.2 Respiratory Symptoms

Symptom burden has been associated with increased supportive care needs,[216] reduced quality of life[121, 172, 323] and distress[350] (see Section 5). The presence and severity of respiratory symptoms have a clear role in the diagnosis of lung cancer. It is expected that a cancer of the respiratory system leads to the development and experience of respiratory symptoms; for instance, lung cancer patients are more likely to experience dyspnoea than patients with other cancers.[351, 352]

Dyspnoea is strongly related to distress in lung cancer patients.[353] Furthermore, increased prevalence of respiratory symptoms in the general public is associated with increasing prevalence of lung cancer diagnoses,[353] and the relative risk of lung cancer is related to the number and type of respiratory symptoms.[66, 354] Lung cancer patients experience high levels of distressing dyspnoea and cough in the final year of life.[202] Although many lung cancer patients can be managed as out-patients, the second most frequent symptom leading to in-patient admission has been reported to be dyspnoea; pain was the most frequent.[281] Furthermore, lung cancer patients may also have

concurrent chronic obstructive pulmonary disease (COPD).[189, 190, 268] COPD itself is associated with a high respiratory symptom burden in the last year of life.[178]

The continuation of respiratory symptoms after curative intent surgery for lung cancer has been reported by Sarna et al[269] who noted that co-morbidity was the main factor predicting symptom distress. The reduction in lung function secondary to surgical resection also increases the likelihood of respiratory symptoms irrespective of the result of the surgery. Sarna et al[115] previously reported that, in long-term survivors of NSCLC, dyspnoea is the only respiratory symptom to be independently related to reduced QOL. Again, the presence of dyspnoea was related in part to the presence of co-morbidities. The presence of dyspnoea in lung cancer patients has been reported to be correlated to reduced QOL and anxiety but was not significant as part of a multivariate model.[302] Smith et al[355] found that pain and anxiety scores were significantly higher in lung cancer patients with increased dyspnoea. They found no relationship between dyspnoea and PS, histology, stage of disease or gender.

In the current study, high levels of both dyspnoea and cough were confirmed in the general population, newly diagnosed patients and patients in the last three months of life. Haemoptysis is a lower level symptom but of particular diagnostic relevance (see Section 6.2). In the general clinic population, the presence of dyspnoea was correlated with all POS items except time use. In the last three months of life, dyspnoea was correlated with all POS items except ability to share, practical issues and time use. Cough was correlated with all items in the general population and all items except pain, ability to share, practical issues and time use in patients who died within three months. Although overall respiratory score is not associated with increased supportive care needs in newly diagnosed patients, bivariate correlation shows a relationship between dyspnoea and all POS items except life-worth, information needs, practical issues and time use. Cough was correlated to all items except pain, information needs and time use. Haemoptysis was only correlated with 'other' symptoms and life-worth.

Although cough is a prevalent symptom in the lung cancer population, it appears to be less important in terms of supportive care needs. Sarna et al[269] reported higher prevalence of severe cough than dyspnoea in NSCLC survivors, but only dyspnoea significantly contributed to reduced QOL. Less than 50% of cancer patients with cough rated this as distressing, but around 70% of those with dyspnoea considered the

symptom distressing.[224] This is in keeping with the concept of symptom burden relating not just to the presence of a symptom but also the severity, frequency and subjective distress related to that symptom[121, 162, 165, 169, 309, 324] (see Section 1.5).

7.3.3 Age

The age of a patient with lung cancer may have implications for management decisions and the treatment options available. Although age itself should not exclude any patient from being offered any specific treatments,[227] it has been reported that older patients are less likely to receive active anti-cancer treatments than younger patients in both NSCLC[227] and SCLC.[356] However, when age was controlled for, the major determinants of treatment delivered were found to be PS and presence of co-morbidity.[228] Graves et al[350] reported a higher level of distress (measured by 0-10 visual analogue distress scale) in younger patients with lung cancer (odds ratio 0.97, 95% CI 0.94-0.99, p=0.36). Graves et al[350] found no other demographic factor evaluated was related to distress (i.e. gender, race, stage or treatment type). Kirkova et al[224] found symptom-related distress and symptom severity in cancer patients (24% patients had lung cancer) were independently associated with younger age, lower performance status and gender. Degner and Sloan[119] reported a weak negative correlation between age and symptom distress (r=-0.11, p=0.026), with older patients experiencing less symptom distress. Skaug et al[303] reported that younger age (<65 years) was a significant independent predictor of psychological symptoms in the last two months of life in lung cancer patients. However, Ferreira et al[323] reported no independent effect of age on overall quality of life. Sanders et al[216] found no independent relationship between age and supportive care needs (measured by the supportive care needs survey) in lung cancer patients. None of the subscales were significantly associated with age in this study (i.e physical, information, psychological or patient care needs).

In contrast to Sanders et al,[216] in the current study age was a significant factor in the general clinic population and newly diagnosed patients. It was not significant in the last three months of life. In particular, younger age was correlated with increased personal anxiety, perceived support network anxiety and practical needs in these clinical groups. In newly diagnosed patients, pain was also correlated to lower age. The finding that younger patients experience more psychological distress in cancer is well documented for several cancer types.[224, 341, 357] The relationship between psychological distress and age has been most studied in the setting of breast cancer care. It has been suggested that

for younger patients the potential losses due to a diagnosis of cancer are greater; that is, work, fertility and time with children. Others have argued that, through life experience, resilience develops and older patients have greater psychological resources to draw on at the time of cancer diagnosis.[357] Furthermore, Jorm[358] reviewed the literature to evaluate whether old age reduces the risk of anxiety and depression in the general population. He concluded that a clear answer is difficult due to multiple possible confounding variables, but overall there may be evidence of reduced psychological and emotional responsiveness as age increases. This age-related effect could be explained by increased emotional control and 'psychological immunisation' to stressful events through prior exposure. In a further community survey of participants aged between 20 and 64, Jorm et al[359] reported a reduction in both anxiety and depression overall as age increases. It appears that, in lung cancer, younger patients are more likely to experience anxiety but the reasons for this require further elucidation. This finding is important and suggests that, in lung cancer care, increased vigilance should be adopted in assessment of psychological supportive care needs of younger patients.

7.3.4 Non-Significant Factors

7.3.4.1 Time from Diagnosis

It has been reported that psychological and spiritual distress in lung cancer varies over different phases of the lung cancer journey. Weisman and Worden[4] first described a peak symptom distress in the first 100 days of lung cancer. In their qualitative study, Murray et al[180] have described peaks of psycho-spiritual distress at diagnosis, at discharge from hospital and at times of recurrence. In this study, physical function and social distress declined as lung cancer advanced. Worden[360] also went on to describe the distress experienced during recurrence of any cancer type. A peak in psychological distress around diagnosis has also been described by Cooley et al[174] Furthermore, Montazeri et al[342] reported significant pre-diagnosis depression in lung cancer patients that reduced during follow-up.

Physical symptoms have been reported to increase as lung cancer advances.[12, 178, 179, 297] However, Sanders et al[216] found no independent relationship between time from diagnosis and supportive care needs in lung cancer patients when controlling for physical function, coping mechanism, symptom bother, distress, healthcare satisfaction and depression in a stepwise logistic regression. It should be noted that time from diagnosis does not necessarily imply progressive or advanced lung cancer. Survivors of

lung cancer will be increasingly represented in any sample that is distant from diagnosis date, and this is likely to lead to a bias in cross-sectional studies of heterogeneous lung cancer populations. Thus, time from diagnosis should be considered separately from stage of lung cancer. Survivors of lung cancer are likely to continue to have supportive care needs.[361] Physical symptoms may have been a legacy of the curative treatments provided[115, 269] or may relate to significant co-morbidities.[361] Psychosocial distress may continue from the previous diagnosis, reflect altered physical function[115] despite cure or result from use of resources during the lung cancer.[361, 362] In the current study, supportive care needs were independent of 'time from diagnosis' and this is an important finding affirming the need for supportive care from early on in the lung cancer journey. Therefore, time from diagnosis should not alter supportive care needs being evaluated and addressed.

7.3.4.2 Gender

Degner and Sloan[119] utilised univariate analysis to evaluate patients with a variety of cancers. They found significantly higher symptom distress in females compared to males and again in advanced stage disease compared to early stage cancers. Increased symptom distress in females was also reported by Cooley et al.[174] However, Graves et al[350] reported no difference between genders in relation to symptom distress and psychosocial distress, and Ferreira et al[323] reported no independent effect of gender on overall quality of life. Skaug et al[303] reported that in the last two months of life gender had no relationship to physical or psychological symptoms. Sanders et al[216] also found no independent relationship between gender and supportive care needs (measured by the supportive care needs survey) in lung cancer patients. In the current study, the level of supportive care needs was not dependent on gender. Although some previous studies have suggested females experience more symptom and psychological distress, this was not observed in many other studies. Supportive care should, therefore, be available, targeted and offered to both males and females with lung cancer.

7.3.4.3 Stage

In studies of lung cancer patients, Cooley et al[174] found no relationship between symptom distress and stage of disease at diagnosis, three months or six months post-diagnosis. Graves et al[350] reported no relation between stage and symptoms or psychosocial distress in lung cancer patients. Sanders et al[216] found no independent

relationship between stage and supportive care needs. However, Skaug et al[303] reported differences in self-reported pain and nausea in the last two months of life in relation to stage of lung cancer. Lutz et al[297] also reported increased symptom burden in those with advanced lung cancer and those patients in the last few months of life.

In the current study, there was no direct relationship between stage of lung cancer and level of supportive care needs. In particular, the presence of metastases did not necessarily mean higher supportive care needs. Stage of disease should not be used to target supportive care in the lung cancer clinic.

7.3.4.4 Histology

Cooley et al[174] also described an independent association between symptom distress and histology in newly diagnosed patients (NSCLC > SCLC symptom distress) but not at six months post-diagnosis. Skaug et al[303] reported that patients with SCLC were more likely to have nausea and psychological symptoms in the last two months of life than those with NSCLC or no histology. Graves et al[350] reported no relation between histology and symptoms or psychosocial distress in lung cancer patients. Differences between physical symptoms, function and psychosocial distress between histological types in lung cancer reflect a complex of potential variables. NSCLC and SCLC have different patterns of disease burden, different treatment protocols, possible differences in paraneoplastic syndromes and different mortality rates. As such, it is difficult to pin-point particular reasons for described differences in supportive care needs. In the current study, histology was not independently related to levels of supportive care needs. Thus, histology in itself should not be used as a means of targeting supportive care.

7.3.4.5 Treatment

Sarna et al[284] reported increased symptom distress in patients receiving chemotherapy and those not receiving surgery. Cooley et al[174] did not find any association between symptom distress and treatment delivered at diagnosis (first 100 days) or at six months post-diagnosis. However, at three months post-diagnosis, patients who had undergone surgery had significantly less symptom distress than those who received radiotherapy or chemotherapy. Graves et al[350] reported no relationship between treatment type and symptoms or psychosocial distress in lung cancer patients.

In the current study, the delivery of active anti-cancer treatment did not predict the levels of supportive care needs. This is consistent with the current trend to integrate palliative and supportive care early into lung cancer management, including those who are receiving active treatment (see Section 1.4.7).

7.3.4.6 Deprivation

Lung cancer is more prevalent in deprived populations; it has been postulated that this relates to a higher smoking prevalence.[333, 334] This association has also been observed in Scotland.[52] Deprivation has been associated with reduced survival[52, 336] and increased symptom burden in lung cancer.[53] Montazeri et al[53] reported that deprivation level was associated with increased pain, increased dyspnoea, increased peripheral neuropathy, reduced functioning, reduced role functioning and reduced energy in lung cancer patients. This univariate analysis also found that the differences between socio-economic groups were less apparent during follow-up than at diagnosis. However, several other studies have found no independent association between deprivation level and symptom distress[174, 323, 350] or quality of life in lung cancer.[323]

In the current study, there was a high level of deprivation within the lung cancer population. However, no relationship between deprivation and supportive care needs was identified. Thus, it could be recommended that deprivation levels should not be used to target supportive care. This was an unexpected finding, but it can be speculated that because most patients were deprived on the whole (to varying degrees), potential differences in supportive care needs within the study population were not identifiable.

7.4 Conclusions

Comparisons with previous studies show inconsistencies that reflect the variability in methodology, selection criteria, assessment tools, co-variates evaluated and outcome measures. However, a clear role is identified for the use of ECOG PS and respiratory symptoms as helpful clinical markers indicating possible higher supportive care needs at any stage of the lung cancer journey. Younger patients may also experience higher psychosocial distress, and vigilance for this should be adopted when caring for patients under 65 years. In contrast to the Sanders et al[216] conclusion that supportive needs are not predicted by readily available clinical information, the current study establishes that ECOG PS and presence or absence of respiratory symptoms identify many patients with

higher needs. Respiratory symptom assessment remains an integral part of lung cancer follow-up, and ECOG PS is already used to direct clinical decisions regarding fitness for active anti-cancer treatments in many multidisciplinary clinics. As such, these two practical clinical approaches could be utilised within a clinic setting, perhaps incorporated into a nurse-led follow-up protocol or to allow community based follow-up of patients not undergoing hospital-based interventions.

8 Supportive Care Needs and Survival

In keeping with Aim 4b, this section evaluates possible predictors of reduced survival within the Stobhill lung cancer population. The predictors evaluated were all readily available within the Stobhill clinic and may serve to allow effective and efficient targeting of supportive care for those who have less time. The methodology and statistical approach are outlined in Section 3.

8.1 Introduction

Lung cancer is a disease of short survival and high mortality[3] (see Section 1). Treatments are employed to improve survival, provide palliation or both. The most consistent and useful predictors of survival are extent of disease, performance status, weight loss and tumour histology.[100, 126, 128] However, a variety of other factors have been identified to be adverse prognostic factors in lung cancer. These include raised C-reactive protein, reduced albumin, age, gender, smoking status and a variety of physiological markers.[100, 363] There is also some evidence that symptom burden and quality of life may affect prognosis.[1, 183, 309] The relationship between survival and supportive care needs, as measured by POS, are explored here.

8.2 Results

8.2.1 Survival of All Patients Attending the Lung Cancer Clinic

	Survival in days		95% Confidence interval		Log Rank comparison			
Factor	Median	SE	Lower	Upper	χ^2	Df	p value	Significant
Overall survival								
	319	0.25	269.27	368.73	na			
Gender								
Male	274	30.41	214.41	333.59	2.92	1	0.088	
Female	354	45.41	264.99	443.01	2.92	1	0.088	
Age								
<65 years	307	29.17	249.83	364.17				
≥65 years	319	41.90	236.88	401.12	0.12	1	0.729	
Histology								
Clinical	422	109.20	207.97	636.03				
NSCLC	326	35.91	255.62	396.38				
SCLC	181	57.25	68.80	293.20	7.68	2	0.022	*
Presence or absence of metastases								
None	441	77.92	288.27	593.73				
Metasases	136	23.50	89.94	182.06	42.01	1	<0.001	***
Weight loss since diagnosis?								
No	394	82.70	231.91	556.09				
Yes	255	38.47	179.59	330.41	6.00	1	0.014	*
Performance status rated by patients								
0-1	394	65.99	264.65	523.35				
2-4	229	26.94	176.20	281.80	14.40	1	<0.001	***
Diagnosis PS, assessed by doctor								
0-1	394	52.02	292.03	495.97				
2-4	198	49.42	101.14	294.86	12.57	1	<0.001	***
Palliative outcome scale								
<10	360	49.91	262.17	457.83				
>10	248	45.99	157.86	338.14	5.47	1	0.019	*
Active anti-cancer treatment								
Yes	354	35.74	283.95	424.05				
No	198	45.24	109.34	286.66	5.68	1	0.017	*
Deprivation								
Dep Cat 1-5	280	31.39	218.47	341.53				
Dep cat 6 or 7	338	43.33	253.06	422.94	0.41	1	0.524	
Respiratory symptom score								
0-4	331	37.44	257.62	404.38				
5-8	283	69.71	146.36	419.64				
9-12	252	187.79	0.00	620.08	5.15	2	0.076	

Table 52: Comparisons of median survival and confidence intervals for all patients attending the lung cancer clinic. *p<0.05, **p<0.01 and ***p<0.001

Overall median survival from LCQ completion in this heterogeneous population of all patients (newly diagnosed and returning patients) was 319 days (10.6 months). Factors that were significantly associated with reduced survival from time of LCQ completion were: histology (SCLC worst survival), presence of metastases, weight loss since diagnosis, reduced PS (patient or doctor-rated), POS score greater than ten, not receiving active anti-cancer treatment (Figure 18A and B). There was no difference in survival between genders, higher and lower deprivation level, younger and older patients and respiratory symptom score groups. However, for increasing respiratory symptom score, there was a trend toward poorer survival.

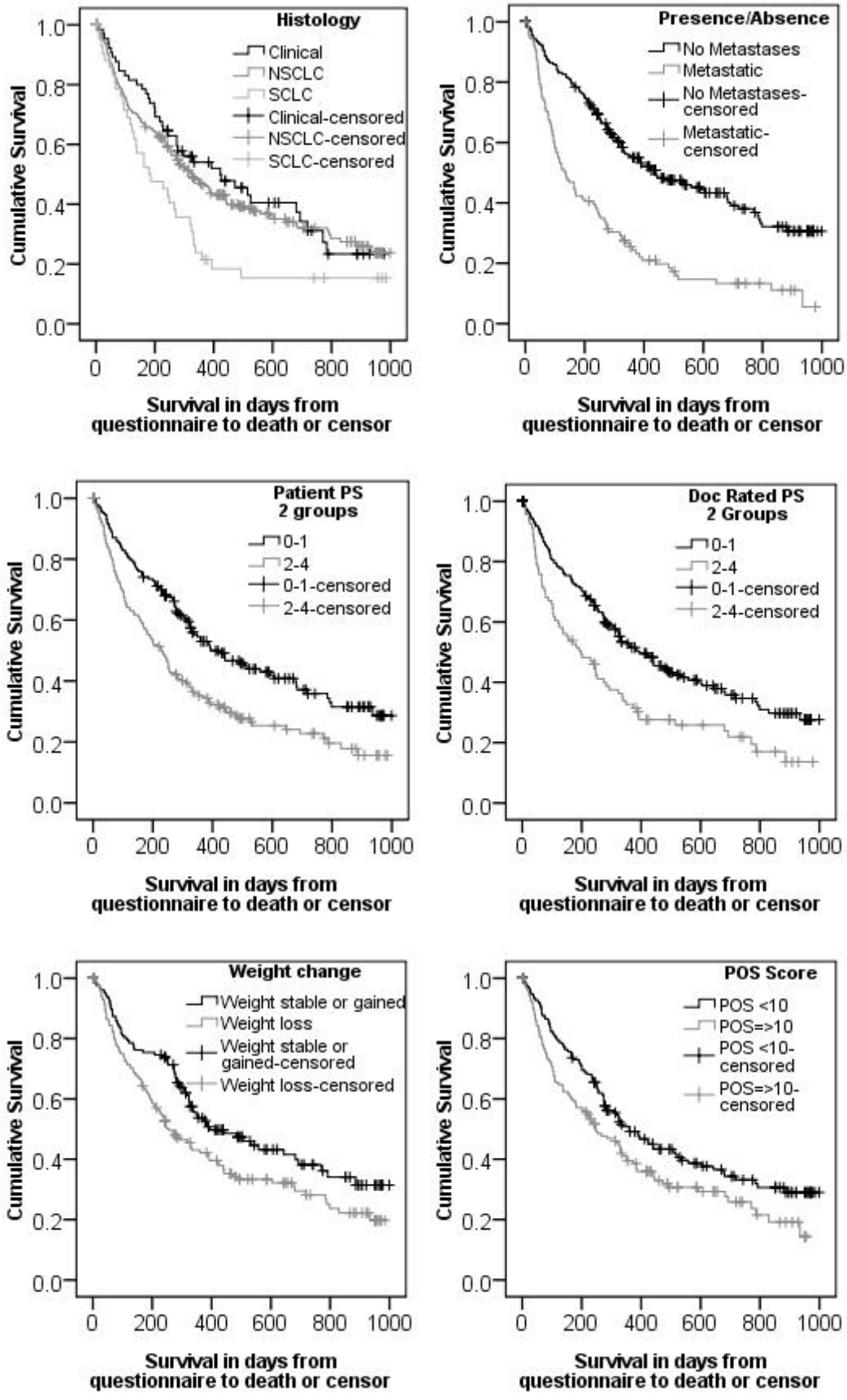


Figure 18A: Kaplan-Meier curves for survival from questionnaire completion until death or censor for all patients attending the lung cancer clinic.

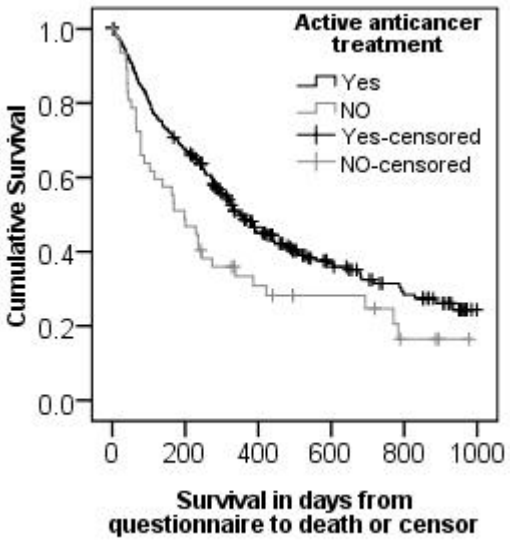


Figure 18B: Kaplan-Meier curve for survival from questionnaire completion until death or censor for all patients attending the lung cancer clinic.

						95% CI for Hazard Ratios		
	b	SE	Wald	df	p value	Hazard Ratio	Lower	Upper
PS = 0			14.235	2	.010			
PS = 1-2	.428	.230	3.465	1	.063	1.534	.978	2.408
PS = 3-4	.735	.197	13.938	1	<0.001	2.085	1.418	3.065
Weight loss	.431	.178	5.865	1	.150	1.539	1.086	2.182
Metastatic disease	.942	.178	27.842	1	<0.001	2.564	1.807	3.638

Model $X^2 = 49.957$, df = 4, p>0.001

Table 53: Backwards Cox regression. Factors identified as independently associated with reduced survival in all patients attending the lung cancer clinic.

Factors identified as independent predictors of reduced survival from LCQ completion were: Poorer ECOG PS, weight loss from diagnosis and presence of metastatic disease.

8.2.2 Survival of Newly Diagnosed Patients Attending the Lung Cancer Clinic

	Survival in days		95% Confidence interval		Log Rank comparison			
Factor	**Median**	**SE**	**Lower**	**Upper**	**χ^2**	**Df**	**p value**	**Significant**
Overall survival								
	266	33.69	199.96	332.04				
Gender								
Male	235	58.53	120.28	349.72				
Female	277	44.40	189.98	364.02	1.05	1	0.305	
Age								
<65 years	277	53.77	171.61	382.39				
≥65 years	252	42.52	168.66	335.34	0.00	1	0.988	
Histology								
Clinical	422	103.68	218.79	625.21				
NSCLC	232	47.92	138.08	325.92				
SCLC	248	24.62	199.74	296.26	3.87	2	0.145	
Presence or absence of metastases								
None	422	110.97	204.50	639.50				
Metasases	103	28.35	47.44	158.56	25.47	1	<0.001	***
Weight loss since diagnosis?								
No	349	92.43	167.84	530.16				
Yes	240	56.01	130.21	349.79	2.08	1	0.149	
Performance status rated by patients								
0-1	389	55.95	279.33	498.67				
2-4	178	25.06	128.88	227.12	7.63	1	0.006	**
Diagnosis PS, assessed by doctor								
0-1	360	61.76	238.95	481.05				
2-4	151	47.14	58.61	243.39	8.87	1	0.003	**
Palliative outcome scale								
<10	360	75.93	211.17	508.83				
>10	201	47.86	107.20	294.80	4.39	1	0.036	*
Active anti-cancer treatment								
Yes	326	36.61	254.24	397.76				
No	138	64.91	10.78	265.22	3.80	1	0.051	
Deprivation								
Dep Cat 1-5	248	46.59	156.68	339.32				
Dep cat 6 or 7	277	55.00	169.19	384.81	0.07	1	0.786	
Respiratory symptom score								
0-4	277	51.74	175.58	378.42				
5-8	252	96.12	63.60	440.40				
9-12	22	.	.	.	3.31	2	0.209	

Table 54: Comparisons of median survival and confidence intervals for newly diagnosed patients attending the lung cancer clinic. *p<0.05, **p<0.01 and ***p<0.001

Overall median survival from LCQ completion in this population of newly diagnosed patients was 266 days (8.87 months). Factors identified as significantly associated with reduced survival from time of LCQ completion were: presence of metastases, reduced PS (patient or doctor-rated) and POS score greater than ten (Figure 19).

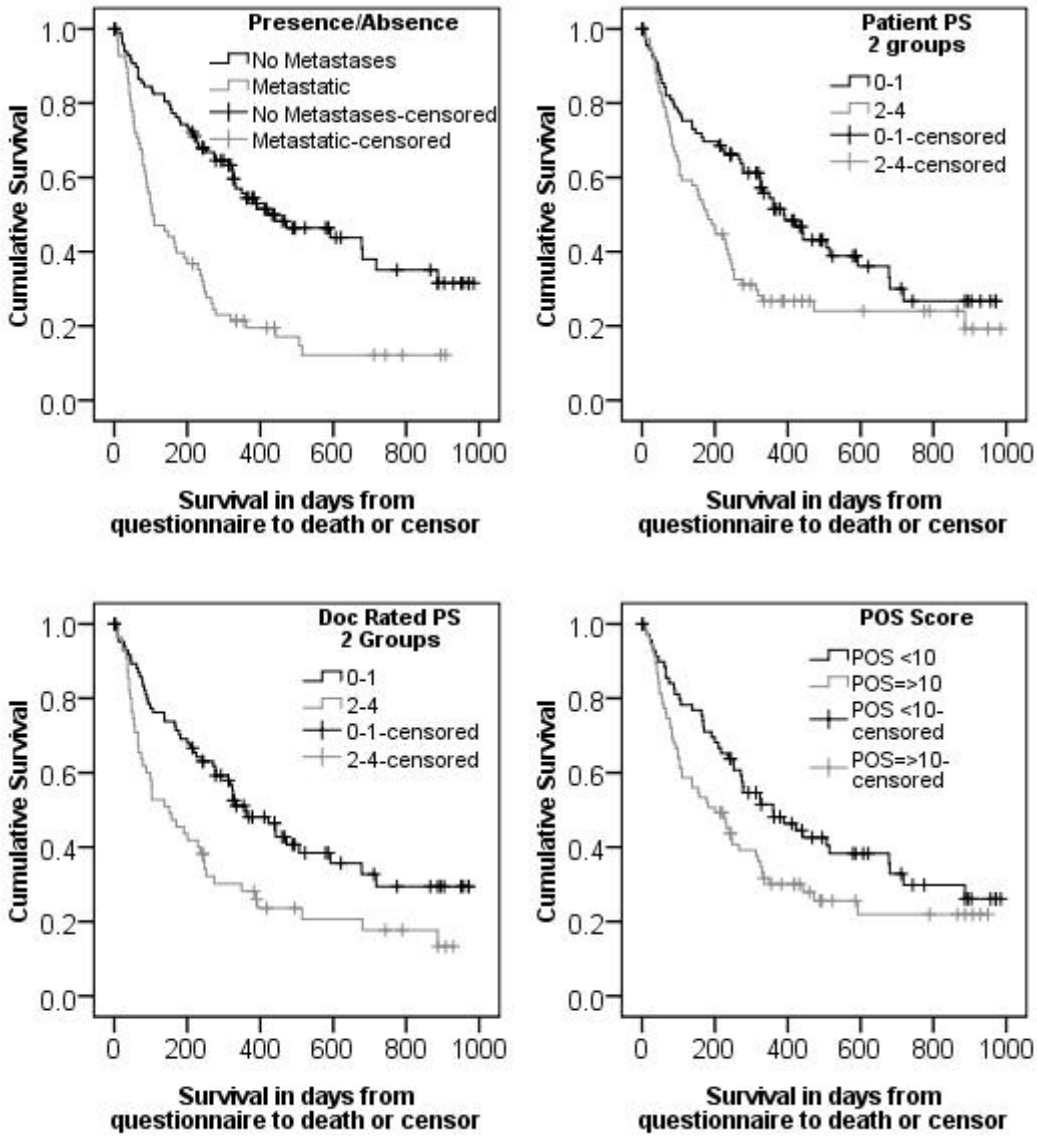


Figure 19: Kaplan-Meier curves for survival from questionnaire completion until death or censor for newly diagnosed patients.

						95% CI for Hazard Ratios		
	b	SE	Wald	df	p value	Hazard Ratio	Lower	Upper
Metastatic disease	.667	.235	8.086	1	.004	3.19	2.00	5.10
PS = 0			7.115	2	.029			
PS = 1-2	.350	.313	1.248	1	.264	1.419	.768	2.622
PS = 3-4	.706	.265	7.105	1	.008	2.025	1.205	3.403

Model $X^2 = 37.053$, df = 3, p>0.001

Table 55: Backwards Cox regression. Factors identified as independently associated with reduced survival in newly diagnosed patients attending the lung cancer clinic.

Factors identified as independent predictors of reduced survival from LCQ completion were: presence of metastatic disease and the ECOG PS.

8.2.3 Survival of Patients in the Last Three Months of Life

Overall median survival from LCQ completion in this population of patients in the last three months of life was 41 days. Factors identified as significantly associated with reduced survival from time of LCQ completion were: increased dyspnoea, pain, personal anxiety and increased ability to share (Figure 20).

	Survival in days		95% Confidence interval		Log Rank comparison			
Factor	Median	SE	Lower	Upper	χ^2	Df	p value	Significant
Overall survival								
	41	3.54	34.07	47.93	na			
Gender								
Male	33	6.32	20.62	45.38				
Female	44	3.71	36.73	51.27	0.01	1	0.904	
Age								
<65 years	44	5.48	33.26	54.74				
≥65 years	41	4.33	32.51	49.49	0.25	1	0.620	
Histology								
Clinical	49	6.53	36.20	61.80				
NSCLC	40	3.60	32.94	47.06				
SCLC	36	6.10	24.04	47.96	1.00	1	0.606	
Presence or absence of metastases								
None	39	10.33	18.76	59.24				
Metasases	42	4.39	33.39	50.61	0.02	1	0.876	
Weight loss since diagnosis?								
No	47	7.65	32.01	61.99				
Yes	45	2.92	39.27	50.73	0.00	1	0.969	
Performance status rated by patients								
0-1	38	11.86	14.76	61.24				
2-4	41	3.50	34.14	47.86	0.01	1	0.927	
Diagnosis PS, assessed by doctor								
0-1	42	5.10	32.00	52.00				
2-4	44	3.99	36.18	51.82	1.15	1	0.283	
Palliative outcome scale								
<10	39	5.24	28.72	49.28				
>10	43	5.08	33.05	52.95	0.07	1	0.788	
Active anti-cancer treatment								
Yes	37	4.61	27.97	46.03				
No	49	3.99	41.17	56.83	1.07	1	0.300	
Deprivation								
Dep Cat 1-5	44	5.18	33.84	54.16				
Dep cat 6 or 7	39	3.74	31.67	46.33	0.89	1	0.344	
Respiratory symptom score								
0-4	44	4.72	34.75	53.25				
5-8	42	4.32	33.54	50.46				
9-12	22	.	.	.	1.66	2	0.435	
Dyspnoea								
Lower	50	9.18	32.01	67.99				
Higher	38	6.25	25.74	50.26	4.27	1	0.039	*
Cough								
Lower	45	5.33	34.55	55.45				
Higher	41	4.46	32.27	49.73	1.67	1	0.196	
Haemoptysis								
Lower	41	3.56	34.01	47.99				
Higher	66	24.88	17.24	114.76	2.89	1	0.089	
Pain								
Lower	45	6.93	31.42	58.58				
Higher	37	7.12	23.05	50.95	8.00	1	0.005	**
Other symptoms								
Lower	45	4.84	35.52	54.48				
Higher	41	4.37	32.43	49.57	0.24	1	0.622	
Personal anxiety								
Lower	47	2.53	42.05	51.95				
Higher	37	3.97	29.22	44.78	4.45	1	0.035	*
Support network anxiety								
Lower	46	6.03	34.18	57.82				
Higher	41	3.03	35.05	46.95	0.87	1	0.351	
Ability to share								
Lower	37	3.19	30.75	43.25				
Higher	49	5.66	37.91	60.09	6.94	1	0.008	**
Self-esteem								
Lower	46	5.34	35.53	56.47				
Higher	36	6.78	22.72	49.28	0.93	1	0.336	
Life-worth								
Lower	44	3.20	37.73	50.27				
Higher	26	6.45	13.36	38.64	0.11	1	0.736	

Table 56: Comparisons of median survival and confidence intervals for patients in the last 3 months of life. *p<0.05, **p<0.01 and ***p<0.001

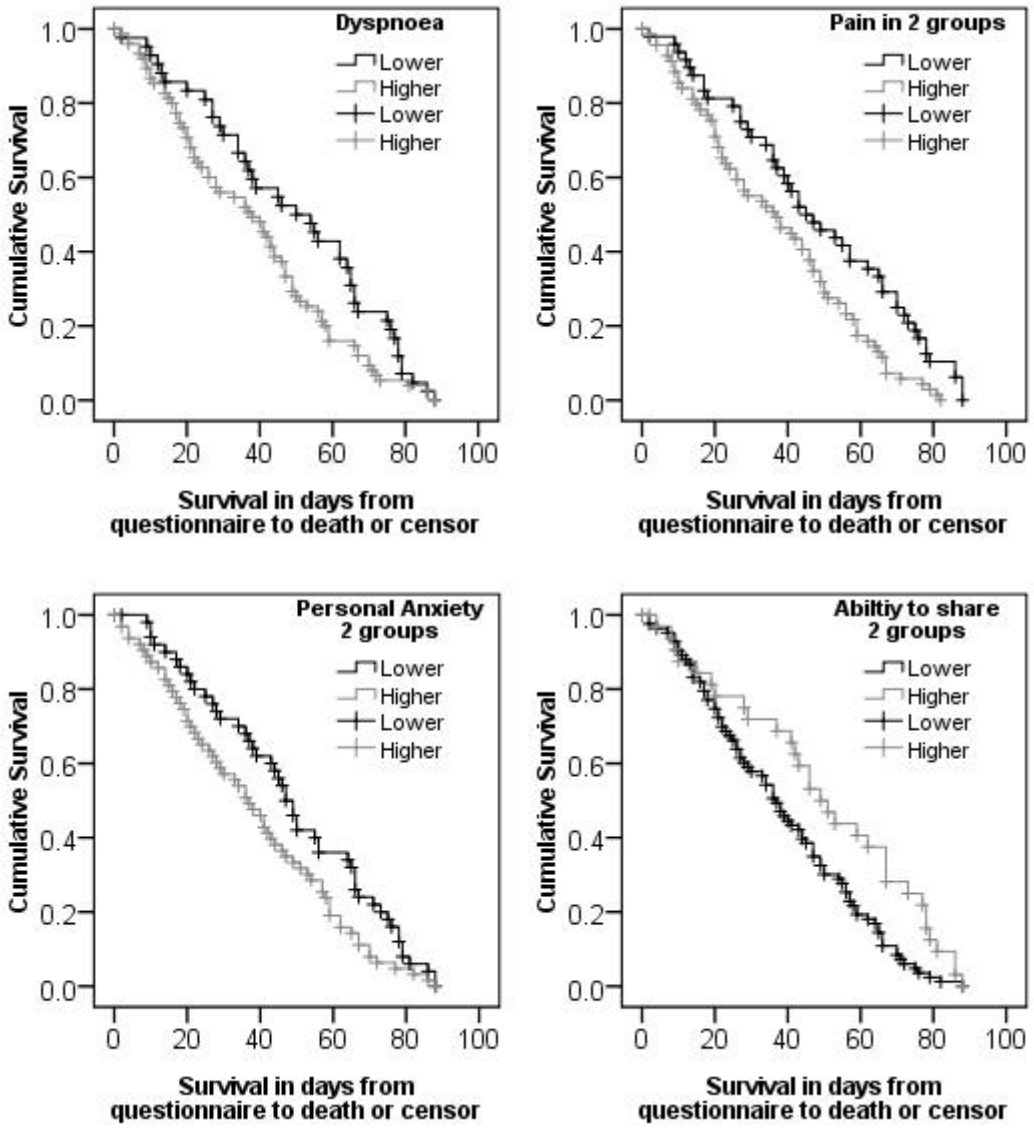


Figure 20: Kaplan-Meier curves for survival from questionnaire completion until death or censor for patients who died within three months of questionnaire completion

						95% CI for Hazard Ratios		
	b	SE	Wald	df	p value	Hazard Ratio	Lower	Upper
Dyspnoea (higher)	.401	.204	3.851	1	.050	1.493	1.001	2.229
Pain (higher)	.490	.205	5.719	1	.017	1.633	1.093	2.441
Reduced ability to share	-.557	.217	6.567	1	.010	.573	.374	.877

Model $X^2 = 20.388$, df = 2, p>0.001

Table 57: Backwards Cox regression. Factors identified as independently associated with reduced survival in patients in last 3 months of life.

Factors identified by logistic regression as independent predictors of reduced survival from LCQ completion were: increased pain, dyspnoea and increased ability to share.

8.3 Discussion

Lung cancer is a disease of reduced survival. Prognostication in lung cancer serves several purposes and includes aiding decision-making regarding treatments offered,

helping patients make decisions regarding accepting treatments,[364] affording some guidance to patients regarding survival outlook, influencing goals of treatments and identifying the most appropriate healthcare professional to lead care provision. Despite the median survival of lung cancer remaining relatively unchanged for the last 25 years, determining prognosis on an individual level remains difficult but no less important. The main clinical indicators of prognosis that have previously been identified are stage of disease, performance status and weight loss. Additional refinement of the prognosis estimate is informed by additional clinical markers (e.g. LDH) and laboratory markers of systemic inflammation or nutritional status. In addition to these, there have been several reports regarding the potential prognostic value of patient-derived indices such as quality of life, symptom burden and supportive care needs.

In the current study, several factors have been confirmed as independent adverse prognostic factors. In the general population attending the Stobhill lung cancer clinic, performance status, presence of metastases and weight loss were all independent adverse prognostic factors. This is in keeping with previous reports which have identified these factors as key in both prognostication and decision-making in lung cancer (see Section 1.4.5). In newly diagnosed patients, ECOG PS and the presence of metastases were significant. In the final three months of life, none of the above factors was significant, but instead increased pain, increased dyspnoea and increased ability to share were independent predictors of reduced survival time. It is possible that as patients near the end of life, reduced PS and weight loss are so common that these factors lose discriminating prognostic power.

In the general clinic population and in newly diagnosed patients, increased supportive care needs as measured by POS (POS≥10) were associated with reduced survival time on univariate analysis. This association was not maintained when controlling for other factors in multivariate analysis. In Section 7, it was established that the key predictor of supportive care needs was performance status. Given this strong relationship and the knowledge that performance status is also a strong predictor of survival, it is not surprising to find that supportive care needs are not significant predictors of survival when controlling for the effect of PS and other known adverse prognostic factors.

Although POS≥10 was not a significant factor in the last three months of life, the previously documented adverse prognostic physical symptoms of pain and dyspnoea

were found to be the main independent factors in this population of lung cancer patients. Furthermore, PS, presence of metastatic disease and weight loss were not found to be significant predictive factors. It has previously been described that in the terminal phase, histology and stage of disease have less importance in predicting prognosis.[133, 134]

8.3.1 Symptoms, Supportive Care Needs and Survival in Lung Cancer

Symptoms may be predictive of mortality in cancer.[1, 183, 309] In lung cancer there is specific evidence of a relationship between increased symptom distress and decreased survival. The Degner & Sloan[119] analysis of 82 lung cancer patients in a wider cohort of 434 ambulatory, newly diagnosed cancer patients showed a significant negative correlation between symptom distress (measured by the SDS) and survival. This relationship held true when symptom distress was measured any time in the six months following diagnosis. However, they reported three patients with high symptom distress but greater than five years' survival. On further review, these patients had undergone thoracotomies and had significant post-surgical pain at time of testing. This was noted as a limitation of symptom assessment for aiding prognostication. Kasaa et al[120] had previously found that inoperable lung cancer patients with low symptom distress survived longer than those with higher levels of distress, irrespective of treatment. Kukull et al[181] also found a negative correlation with higher symptom distress (measured by the SDS) and survival when controlling for age, personality traits (e.g. coping ability) and functional status.

It has recently been reported that Korean patients with lung cancer who were asymptomatic at presentation survived longer than those who were symptomatic at presentation.[173] In this large, national survey of 8788 patients diagnosed with lung cancer in 2005, only 6.5% presented with no symptoms, and 60% of asymptomatic patients underwent curative intent surgery. Furthermore, those asymptomatic patients with NSCLC had reduced risk of death from lung cancer regardless of age, gender, stage at diagnosis, smoking history and whether treatment was given. Interestingly, this was not the case for the asymptomatic patients with SCLC in this cohort.

Global QOL or domains from within QOL assessment may also be an independent predictor of mortality in lung cancer at different stages of disease.[115, 117, 120, 325-331] The relationship between QOL and symptom burden is complex and ill-defined. There are

many tools available for assessing QOL in cancer in general and in lung cancer specifically.[322] Although many of these contain physical symptom components,[323] they differ from symptom (or symptom distress) assessment and needs assessment. Symptom burden may predict overall QOL,[121, 323] but it is not clear if this is an independent effect or relates to the functional effects of symptoms.[172] In some chemotherapy trials, global QOL did not change, but symptom burden measures did show a response to treatment.[324] During active treatment, symptom burden may vary due to occurrence of treatment-related symptoms and improved or worsening disease-related symptoms. Supportive care needs assessment is likely to overlap with both QOL and symptom burden assessment, incorporating physical symptoms, psychosocial domains and functional status dependent domains.[216]

To date there have been no studies specifically examining the relationship between supportive care needs and survival in lung cancer. Furthermore, there have been no studies evaluating the relationship between POS and survival in lung cancer.

In the current study, increased supportive care needs as measured by the Palliative Outcome Scale (POS≥10) were associated with reduced survival in the general clinic population and newly diagnosed patients on univariate analyses. In those who died within three months of questionnaire completion, no relationship was identified between POS and survival. On multivariate analysis, increased supportive care needs were not found to be independent predictors of reduced survival in any of the groupings.

In the last three months of life, increased ability to share was associated with reduced survival; it is not clear why this is the case. It may be that as patients enter the terminal phase, they consider sharing thoughts and worries more and therefore increase the perception of feeling listened to. It may also be that patients nearing death are given more opportunities to discuss their worries and feelings about their illness.

It has been shown that PS is a strong predictor of both increased supportive care needs (see Section 7) and reduced mortality. It is not surprising, therefore, that when controlling for the effects of PS and other known adverse prognostic factors, increased supportive care needs do not predict reduced survival.

In the current study, PS was not a significant predictor of survival in the last three months of life. Instead, dyspnoea and pain were identified as the main predictors of survival in the last three months of life. This partly contrasts to previous studies that reported functional status as an important prognostic factor in the terminal stage of cancer.[135] Dyspnoea has been previously reported as a predictor in the terminal phase.[135] This physical symptom is incorporated into prognostic scoring systems used within the palliative setting. Pain has also been found to be associated with reduced survival in some bivariate cancer studies.[135] Vigano et al,[135] in their review of prognostic factors in terminal cancer, reported that only one study found pain to be an independent predictor of reduced survival. However, it is of note that this finding was reported in a study of lung cancer patients in the last months of life.[365] It has been reported that the type, stage and histology of cancer matter much less in survival prediction in the terminal phase.[135, 366] The current study supports these previous findings.

8.3.2 Additional Factors and Survival in Lung Cancer

Survival from questionnaire completion was not associated with gender, age or deprivation level in any group using univariate analysis. In NSCLC, Albain et al[367] described patients with good performance status, female gender and age of less than 70 years having improved survival. In the current study, there was no significant survival difference between levels of deprivation. Reduced survival in deprived cancer patients has been previously described, and it has been postulated that it may reflect: delays in presentation, reduced access to services, decreased compliance with treatment, increased co-morbidities and life-style factors.[368] Cancer Research UK statistics show that there is a significant difference in relative survival between affluent and deprived lung cancer patients. However, it is noted that this difference of around 1% is only statistically significant due to the large number of patients evaluated.[51] The current study was unlikely to show such a small effect with the relatively small number of patients and the large number of deprived patients.

Those receiving active anti-cancer treatment survived significantly longer overall and there was a trend toward significance in the newly diagnosed population. This analysis includes those who received palliative intent anti-cancer treatments. There was no significant difference found in the last three months of life. It is unlikely that a survival difference derived from treatment would be identified in a group of patients who were all within the last three months of life.

8.4 Conclusions

Increased supportive care needs were associated with reduced survival on univariate analysis, but there was no independent relationship between reduced survival and increased supportive care needs as measured by POS. As such, although patients with a shorter estimated prognosis should receive prompt attention patients at any stage of the lung cancer journey may have unmet supportive care needs. Therefore supportive care issues should be assessed at in all phases of lung cancer patients attending Stobhill Hospital, not just those near the end of life.

ECOG PS is integrated within lung cancer care in Stobhill and many other cancer services. The role of ECOG PS status in predicting survival in lung cancer is key. Furthermore, it has been established that reduced PS is associated with increased supportive care needs (see Section 7). Thus, evaluation of supportive care needs in patients with poor PS should be timely and efficient, so as to identify and manage the unmet needs of this population who also have reduced survival.

9 Anxiety in Lung Cancer – A Key Supportive Care Need

In keeping with Aim 4c, this section evaluates possible predictors of increased anxiety. The predictors evaluated were all readily available within the Stobhill lung cancer service. The methodology and statistical approach are outlined in Section 3.

9.1 Introduction

Anxiety (both personal and that of a support network) has been identified as a key issue in this study. This is in keeping with previous studies utilising POS.[218] Furthermore, perceived support network anxiety has also been consistently rated the highest issue in previous studies.[218]

Anxiety and worry within the lung cancer population are common, underestimated and impact significantly on quality of life.[2, 13, 107, 176, 369] The impact of anxiety and worry on day-to-day life is reflected in the etymology of both words: 'anxiety' derives from the Latin *anxius* meaning to choke; 'worry' originates from the Anglo-Saxon *wyrgan* meaning to strangle.[163] Manifestations of anxiety can be classed as physical (e.g. sweats, palpitation, gastrointestinal disturbance, panic attacks and dyspnoea), behavioural (e.g. unease, restlessness and reassurance-seeking) and psycho-emotional (e.g. apprehension, recurrent and intrusive thoughts and loss of concentration).[370-372] A spectrum of anxiety is observed within both the general and cancer populations. This includes adaptive anxiety, maladaptive anxiety and classifiable anxiety disorders (such as phobias, panic attacks, generalised anxiety disorders and post-traumatic distress).[373-375] Maladaptive anxiety is out of proportion to the stimulus, and it persists and disrupts function and quality of life.[376]

9.1.1 Anxiety in Cancer

Cancer is a threatening diagnosis. The word 'cancer' has been used in studies to provoke anxiety.[372] Within the cancer population, there is a higher prevalence of anxiety and mixed anxiety-depression than in the general population.[371] It can be difficult to assess for anxiety in cancer as the changing illness trajectory, effect and side effects of treatment and the persistent threat of the diagnosis and associated prognostic uncertainty lead to a dynamic situation.[372] However, anxiety can become a significant, identifiable

problem requiring specific assessment and management. Once identified, management of anxiety in cancer includes good communication, information giving, psychological support and pharmacological interventions.[370-372]

9.1.2 Anxiety in Lung Cancer

Physical decline in advanced cancer in general and lung cancer specifically has been well characterised.[372] Lung cancer is often a short illness with rapid physical decline, high symptom burden and prognosis of weeks or a few months.[1, 157] Anxiety and distress are not predictable by gender, age or stage of lung cancer but may peak at certain stages of disease: diagnosis, identification of disease progression and the beginning of the terminal phase.[129, 180] There is some evidence that anxiety in cancer is associated with poor PS and high symptom burden.[371] As such, lung cancer patients are likely to be at risk of anxiety. The small body of research into this area provides some consistent evidence that psychosocial distress is high in the lung cancer population.[119, 164, 168, 178]

9.1.3 Support Network Anxiety

Individual patients cope with illness and symptoms within the context of relationships with significant others.[12, 377] It has been suggested that sharing feelings with trusted and supportive people can improve emotional and cognitive processing of illness.[378] Lack of positive support may adversely affect this process. In tobacco-related disease, there may be additional elements with guilt or blame related to cigarette smoking. This may also affect ability to discuss issues within the support network.[378]

The concept of distinguishing symptom distress from symptom occurrence is gaining ground.[121, 165, 169] Assessment of symptom occurrence and symptom distress may differ between individuals, caregivers and significant others.[165, 167, 169] Lack of concordance in distress recognition and identification of its cause, between patients and others, may influence a patient's perception of support.

Patient perception of family's or friends' worry may affirm presence of support or may drive personal anxiety. Perceiving high anxiety within your support network may impact on freedom to discuss illness or symptoms within the support network.

Conversely, if this perceived anxiety is recognised as appropriate and reflective of care, then it may affirm feelings of support and facilitate shared feelings.

This section further examines anxiety felt by lung cancer patients and the anxiety that they perceive in their support network.

9.2 Results

9.2.1 Anxiety in All Patients Attending the Lung Cancer Clinic

Personal anxiety felt (mean 1.63, median 1, range 0-4, SD 1.31) was reported to be low (0-1) in 49% (n=173/353) of patients. Higher anxiety levels (2-4), were described in 46% of patients (n=161/353). Perceived support network anxiety (mean 2.17, SD 1.40, median 2, range 0-4) was reported to be low (0-1) by 37.1% (n=131/353) of patients and high (2-4) by 56.9% (n=201/353). Being able to share feelings (mean 0.75, SD 1.19, median 0, range 0-4) was reported to be felt possible 'as much as I want' (0) or 'most of the time' (1) in 72.8% (n=257/353) of patients.

9.2.1.1 Personal Anxiety (All Patients)

Personal anxiety was categorised as low (0-1) and high (2-4). Differences between the lower and higher anxiety patients were examined in relation to the factors listed in Table 58. Statistical significance of any difference was assessed (using Pearson X^2 or Fisher's exact test).

	Lower Anxiety		Higher Anxiety					
Factor	Number	Percentage	Number	Percentage	χ^2	Df	p value	Significant
Gender								
Male	92	56.8%	70	43.2%				
Female	81	47.1%	91	52.9%	3.142	1	0.81	
Age								
<65 years	39	41.1%	56	58.9%				
≥65 years	134	56.1%	105	43.9%	6.138	1	0.015	*
Histology								
Clinical	31	50.8%	30	49.2%				
NSCLC	123	53.0%	109	47.0%				
SCLC	19	46.3%	22	53.7%	0.65	2	0.722	
Stage NSCLC								
1A	14	58.3%	10	41.7%				
1B	32	69.6%	14	30.4%				
2A	11	52.4%	10	47.6%				
2B	13	65.0%	7	35.0%				
3A	11	42.3%	15	57.7%				
3B	31	44.9%	38	55.1%				
4	38	46.9%	43	53.1%	10.625	6	0.101	
Stage SCLC								
Limited	7	50.0%	7	50.0%				
Extensive	11	42.3%	15	57.7%	0.218	1	0.641	
Presence or absence of metastases								
None	124	54.6%	103	45.4%				
Metasases	49	45.8%	58	54.2%	2.272	1	0.159	
Time from diagnosis to POS								
Within 3 weeks	43	38.7%	68	61.3%				
3-6 weeks	28	54.9%	23	45.1%				
6 weeks to 3 months	17	53.1%	15	46.9%				
3-6 months	22	57.9%	16	42.1%				
6-12 months	21	53.8%	18	46.2%				
> 12 months	39	65.0%	21	35.0%	12.589	5	0.028	*
Performance status rated by patients								
0-1	111	64.2%	62	35.8%				
2	35	51.5%	33	48.5%				
3-4	27	29.0%	66	71.0%	29.9	2	<0.001	***
Diagnosis PS, assessed by doctor								
0-1	121	57.9%	88	42.1%				
2	24	31.6%	52	68.4%				
3-4	6	66.7%	3	33.2%	16.321	2	<0.001	***
Active anti-cancer treatment								
Yes	134	51.1%	128	48.9%				
No	25	55.6%	20	44.4%	0.299	1	0.63	
Deprivation								
Dep Cat 1-5	76	50.3%	75	49.7%				
Dep cat 6 or 7	94	53.1%	83	46.9%	0.252	1	0.658	
Satisfaction score								
0-4	67	53.6%	58	46.4%				
5-8	1	33.3%	2	66.7%				
9-12	0	.0%	0	.0%	na			
GP attendance between clinics								
No	41	55.4%	33	44.6%				
Yes	35	48.6%	37	51.4%	0.675	1	<0.001	***
Dysnoea								
No	39	63.9%	22	36.1%				
Yes	134	49.1%	139	50.9%	4.40	1.00	0.047	*
Cough								
No	52	65.0%	28	35.0%				
Yes	119	47.2%	133	52.8%	7.68	1.00	0.007	**
Haemoptysis								
No	157	55.5%	126	44.5%				
Yes	14	29.2%	34	70.8%	11.38	1.00	0.001	**
Dysnoea								
Lower	101	62.3%	61	37.7%				
Higher	72	41.9%	100	58.1%	14.02	1.00	<0.001	***
Cough								
Lower	130	61.6%	81	38.4%				
Higher	41	33.9%	80	66.1%	23.67	1.00	<0.001	***
Haemoptysis								
Lower	166	53.4%	145	46.6%				
Higher	5	25.0%	15	75.0%	6.51	1.00	0.019	*
Pain								
Lower	113	58.5%	80	41.5%				
Higher	59	42.4%	80	57.6%	8.39	1.00	0.004	**
Other symptoms								
Lower	156	57.6%	115	42.4%				
Higher	15	25.4%	44	74.6%	20.05	1.00	<0.001	***
Personal anxiety								
Lower	114	87.7%	16	12.3%				
Higher	57	28.4%	144	71.6%	111.29	1.00	<0.001	***
Less ability to share								
Lower	139	55.2%	113	44.8%				
Higher	31	41.3%	44	58.7%	4.43	1.00	0.048	**
Reduced life-worth								
Lower	155	56.8%	118	43.2%				
Higher	8	18.6%	35	81.4%	21.67	1.00	<0.001	***
Reduced self-esteem								
Lower	142	65.7%	74	34.3%				
Higher	24	23.1%	80	76.9%	51.18	1.00	<0.001	***
Information needs								
Lower	126	56.8%	96	43.2%				
Higher	30	36.6%	52	63.4%	9.75	1.00	0.002	**
Practical needs								
Lower	135	56.5%	104	43.5%				
Higher	27	38.0%	44	62.0%	7.47	1.00	0.007	**
Time wasted								
Lower	161	53.0%	143	47.0%				
Higher	4	36.4%	7	63.6%	1.17	1.00	0.362	

Table 58: All patients attending the lung cancer clinic. Univariate analysis of factors across groups of higher and lower anxiety. Percentages adjusted for missing data. *p<0.05, **p<0.01 and ***p<0.001

The significant factors identified by univariate analysis were younger age, time from diagnosis, PS, GP attendance, dyspnoea, cough, haemoptysis, pain, 'other' symptoms, perceived anxiety in support network, reduced ability to share, reduced life-worth, low self-esteem, information needs and practical needs. Patient-rated PS was selected for this model. In addition, other factors of interest from the literature were included in the backwards logistic regression model: gender and presence of metastases. GP attendance was excluded, as this is likely to be a consequence of increased anxiety. The initial model included the factor of perceived anxiety in the support network, and this was the strongest contributor to the model's predictive power. As this perception may have been driven by personal anxiety, the model was repeated excluding this factor. The results of both models are tabulated in Table 59 and Table 60 below.

							95% CI for Odds Ratios	
	b	SE	Wald	df	p value	Odds Ratio	Lower	Upper
Cough (higher)	.701	.326	4.615	1	.032	2.015	1.063	3.818
Family anxiety	2.849	.376	57.313	1	<0.001	17.274	8.261	36.120
Low self-esteem	1.375	.346	15.768	1	<0.001	3.956	2.007	7.798
Constant	-2.692	.371	52.765	1	<0.001	.068		

R^2=0.377 (Cox and Snell); 0.503 (Nagelkerke) Model X^2=135.38, df=3, p<0.001
Hosmer-Lemeshow test: X^2=3.642, df=3, p=0.457

Table 59: Independent factors associated with higher personal anxiety identified through backwards logistic regression for all patients.

A test of the full model against constant only model was statistically significant (model X^2=135.38, df=3, p<0.001). Nagelkerke's R^2 of 0.503 indicated that around 50% of variance was explained by the model. Overall prediction success was 78% (64.1% for lower anxiety and 92.2% for higher anxiety). This compares to the null model overall prediction success of 50.7%. Each of the predictors in the final model was significant at the p<0.05 level. As such, higher levels of personal anxiety in all patients attending the lung cancer clinic were independently associated with perception of increased support network anxiety, increased severity of cough and reduced self-esteem. There were no significant effects from the other variables which were excluded from the final model. For a fixed level of cough and self-esteem, patients who perceived increased anxiety in their support network were 17.274 (95% CI 8.261-36.120) times more likely to have higher levels of personal anxiety (i.e. anxiety which is moderate to overwhelming).

The regression was repeated without including the factor of perceived support network anxiety.

	b	SE	Wald	df	p value	Odds Ratio	Lower	Upper
Performance status 0-1			7.422	2	.024			
Performance status 2	.071	.342	.043	1	.835	1.074	.549	2.099
Performance Status 3-4	.948	.359	6.956	1	.008	2.580	1.276	5.217
Cough (higher)	.782	.288	7.377	1	.007	2.185	1.243	3.840
Low self-esteem	1.379	.323	18.197	1	<0.001	3.970	2.107	7.480
Time from diagnosis >6 months	-.877	.383	5.256	1	.022	.416	.196	.880
Constant	-.859	.203	17.873	1	<0.001	.423		

R^2=0.214 (Cox and Snell); 0.286 (Nagelkerke) Model X^2=69.47, df=5, p<0.001
Hosmer-Lemeshow test: X^2=7.545, df=7, p=0.374

Table 60: Independent factors associated with higher personal anxiety identified through backwards logistic regression for all patients, excluding perceived support network anxiety.

A test of the full model against constant only model was statistically significant (model X^2=69.47, df=5, p<0.001). Nagelkerke's R^2 of 0.286 indicated that around 29% of variance was explained by the model. Overall prediction success was 67.7% (77.6% for lower anxiety and 57.4% for higher anxiety). This compares to the null model overall prediction success of 51%. Each of the predictors in the final model was significant at the p<0.05 level. As such, higher levels of personal anxiety in all patients attending the lung cancer clinic were independently associated with reduced physical function (higher PS), increased cough, lower self-esteem and shorter time from diagnosis. There were no significant effects from the other variables which were excluded from the final model. For a fixed level of cough, self-esteem and time from diagnosis, patients with performance status 3-4 were 2.58 (95% CI 1.276-5.217) times more likely to have higher levels of personal anxiety than those of PS=0.

9.2.1.2 Anxiety Perceived in the Support Network (All Patients)

Anxiety in the support group as perceived by the patient was categorised as low (never anxious to sometimes anxious) and high (most of the time to preoccupied). The analysis was repeated to assess differences between these categories (Table 61).

	Lower Anxiety		Higher Anxiety					
Factor	Number	Percentage	Number	Percentage	χ^2	Df	p value	Significant
Gender								
Male	92	56.8%	70	43.2%				
Female	81	47.1%	91	52.9%	3.142	1	0.81	
Age								
<65 years	39	41.1%	56	58.9%				
≥65 years	134	56.1%	105	43.9%	6.138	1	0.015	*
Histology								
Clinical	31	50.8%	30	49.2%				
NSCLC	123	53.0%	109	47.0%				
SCLC	19	46.3%	22	53.7%	0.65	2	0.722	
Stage NSCLC								
1A	14	58.3%	10	41.7%				
1B	32	69.6%	14	30.4%				
2A	11	52.4%	10	47.6%				
2B	13	65.0%	7	35.0%				
3A	11	42.3%	15	57.7%				
3B	31	44.9%	38	55.1%				
4	38	46.9%	43	53.1%	10.625	6	0.101	
Stage SCLC								
Limited	7	50.0%	7	50.0%				
Extensive	11	42.3%	15	57.7%	0.218	1	0.641	
Presence or absence of metastases								
None	124	54.6%	103	45.4%				
Metasases	49	45.8%	58	54.2%	2.272	1	0.159	
Time from diagnosis to POS								
Within 3 weeks	43	38.7%	68	61.3%				
3-6 weeks	28	54.9%	23	45.1%				
6 weeks to 3 months	17	53.1%	15	46.9%				
3-6 months	22	57.9%	16	42.1%				
6-12 months	21	53.8%	18	46.2%				
> 12 months	39	65.0%	21	35.0%	12.589	5	0.028	*
Performance status rated by patients								
0-1	111	64.2%	62	35.8%				
2	35	51.5%	33	48.5%				
3-4	27	29.0%	66	71.0%	29.9	2	<0.001	***
Diagnosis PS, assessed by doctor								
0-1	96	46.2%	112	53.8%				
2	17	22.4%	59	77.6%				
3-4	4	44.4%	5	55.6%	13.02	2	0.001	**
Active anti-cancer treatment								
Yes	134	51.1%	128	48.9%				
No	25	55.6%	20	44.4%	0.299	1	0.63	
Deprivation								
Dep Cat 1-5	76	50.3%	75	49.7%				
Dep cat 6 or 7	94	53.1%	83	46.9%	0.252	1	0.658	
Albumin at diagnosis								
<35	51	50.0%	51	50.0%				
≥35	117	52.9%	104	47.1%	0.242	1	0.634	
CRP at diagnosis								
<10	84	56.4%	65	43.6%				
≥10	89	48.1%	96	51.9%	2.259	1	0.152	
Glasgow Prognostic Score								
CRP <10 and Albumin >35	66	56.4%	51	43.6%				
CRP >10 or Albumin <35	58	50.4%	57	49.6%				
CRP >10 and Albumin <35	38	46.9%	43	53.1%	1.856	2	0.395	
Satisfaction score								
0-4	67	53.6%	58	46.4%				
5-8	1	33.3%	2	66.7%				
9-12	0	.0%	0	.0%	na			
GP attendance between clinics								
No	41	55.4%	33	44.6%				
Yes	35	48.6%	37	51.4%	0.675	1	<0.001	***
Dysnoea								
No	39	63.9%	22	36.1%				
Yes	134	49.1%	139	50.9%	4.40	1.00	0.047	*
Cough								
No	52	65.0%	28	35.0%				
Yes	119	47.2%	133	52.8%	7.68	1.00	0.007	**
Haemoptysis								
No	157	55.5%	126	44.5%				
Yes	14	29.2%	34	70.8%	11.38	1.00	0.001	**
Pain								
Lower	113	58.5%	80	41.5%				
Higher	59	42.4%	80	57.6%	8.39	1.00	0.004	**
Other symptoms								
Lower	156	57.6%	115	42.4%				
Higher	15	25.4%	44	74.6%	20.05	1.00	<0.001	***
Support network anxiety								
Lower	114	87.7%	16	12.3%				
Higher	57	28.4%	144	71.6%	111.29	1.00	<0.001	***
Less ability to share								
Lower	139	55.2%	113	44.8%				
Higher	31	41.3%	44	58.7%	4.43	1.00	0.048	*
Reduced life-worth								
Lower	155	56.8%	118	43.2%				
Higher	8	18.6%	35	81.4%	21.67	1.00	<0.001	***
Reduced self-esteem								
Lower	142	65.7%	74	34.3%				
Higher	24	23.1%	80	76.9%	51.18	1.00	<0.001	***
Information needs								
Lower	126	56.8%	96	43.2%				
Higher	30	36.6%	52	63.4%	9.75	1.00	0.002	**
Practical needs								
Lower	135	56.5%	104	43.5%				
Higher	27	38.0%	44	62.0%	7.47	1.00	0.007	**
Time wasted								
Lower	161	53.0%	143	47.0%				
Higher	4	36.4%	7	63.6%	1.17	1.00	0.362	

Table 61: All patients attending the lung cancer clinic. Univariate analysis of factors across groups of higher and lower perceived support network anxiety. Percentages adjusted for missing data. *p<0.05, **p<0.01 and ***p<0.001

The significant factors identified by univariate analysis were younger age, time from diagnosis, PS, GP attendance, dyspnoea, cough, haemoptysis, pain, 'other' symptoms, personal anxiety, reduced ability to share, reduced life-worth, low self-esteem, information needs and practical needs. In addition to these factors, gender and presence of metastases were entered into a backwards logistic regression model. Again, GP attendance was excluded. The initial model included the factor of personal anxiety, and it was repeated excluding this factor. The results for both models are tabulated in Table 62 and Table 63.

							95% CI for Odds Ratios	
	b	SE	Wald	df	p value	Odds Ratio	Lower	Upper
Metastases present	.727	.369	3.890	1	.049	2.069	1.005	4.259
Performance status 0-1			9.518	2	.009			
Performance status 2	.758	.410	3.418	1	.064	2.135	.955	4.771
Performance Status 3-4	1.260	.446	7.982	1	.005	3.525	1.471	8.446
Time from diagnosis >6 months	-1.367	.452	9.153	1	.002	.255	.105	.618
Personal anxiety (higher)	2.909	.383	57.759	1	<0.001	18.342	8.662	38.839
Constant	-.924	.250	13.700	1	<0.001	.397		

R^2=0.380 (Cox and Snell); 0.520 (Nagelkerke) Model X^2=137.80, df=5, p<0.001
Hosmer-Lemeshow test: X^2=3.318, df=6, p=0.768

Table 62: Independent factors associated with higher support network anxiety identified through backwards logistic regression for all patients.

A test of the full model against constant only model was statistically significant (model X^2=137.80, df=5, p<0.001). Nagelkerke's R^2 of 0.520 indicated that around 52% of variance was explained by the model. Overall prediction success was 81.3% (81.3% for lower anxiety and 81.3% for higher anxiety). This compares to the null model overall prediction success of 63.27%. Each of the predictors in the final model was significant at the p<0.05 level. As such, higher levels of perceived anxiety in the support network in all patients attending the lung cancer clinic were independently associated with presence of metastases, reduced physical function (increased PS), shorter time from diagnosis and higher personal anxiety. There were no significant effects from the other variables, which were excluded from the final model. For a fixed PS, time from diagnosis and stage of disease (metastatic or not), patients who rated personal anxiety higher were 18.342 (95% CI 8.662-38.839) times more likely to perceive higher levels of anxiety in their support group (i.e. anxiety which is moderate to overwhelming).

	b	SE	Wald	df	p value	Odds Ratio	Lower	Upper
Metastases present	.875	.325	7.235	1	.007	2.399	1.268	4.538
Performance status 0-1			11.939	2	.003			
Performance status 2	.526	.361	2.122	1	.145	1.692	.834	3.432
Performance Status 3-4	1.430	.420	11.581	1	.001	4.180	1.834	9.526
Haemoptysis (higher)	2.033	1.096	3.442	1	.064	7.636	.891	65.416
Low self-esteem	1.129	.372	9.234	1	.002	3.093	1.493	6.407
Time from diagnosis >6 months	-1.365	.379	12.992	1	<0.001	.255	.122	.536
Constant	-.244	.206	1.402	1	.236	.784		

R^2=0.227 (Cox and Snell); 0.310 (Nagelkerke) Model X^2=74.538, df=6, p<0.001
Hosmer-Lemeshow test: X^2=4.823, df=8, p=0.776

Table 63: Independent factors associated with higher support network anxiety identified through backwards logistic regression for all patients. Personal anxiety excluded.

A test of the full model against constant only model was statistically significant (Model X^2=74.54, df=6, p<0.001). Nagelkerke's R^2 of 0.310 indicated that around 31% of variance was explained by the model. Overall prediction success was 72.7% (64.5% for lower anxiety and 77.5% for higher anxiety). This compares to the null model overall prediction success of 63.0%. Each of the predictors in the final model was significant at the p<0.05 level. As such, higher levels of perceived anxiety in the support network in all patients attending the lung cancer clinic were independently associated with presence of metastases, reduced physical function (increased PS), increased haemoptysis, shorter time from diagnosis and reduced self-esteem. There were no significant effects from the other variables, which were excluded from the final model. For a fixed PS, time from diagnosis, presence of higher levels of haemoptysis and stage of disease (metastatic or not), patients who rated reduced self-esteem were 3.093 (95% CI 1.493-6.4079) times more likely to perceive higher levels of anxiety in their support group.

9.2.2 Anxiety in Newly Diagnosed Patients

Personal anxiety felt (mean 1.93, median 2, range 0-4, SD 1.35) was reported to be low (0-1) in 41.8% (n=71/170) of newly diagnosed patients. Higher anxiety levels (2-4) were described by 91 of 170 patients (53.5%). Anxiety perceived in the support network (mean 2.63, SD 1.23, median 3, range 0-4) was reported to be low (0-1) by 22.4% (n=38/170) of patients and described as high (2-4) by 72.4% (n=123/170). Being able to share feelings (mean 0.75, , SD 1.23, median 0.00, range 0-4) was reported to be felt possible 'as much as I want' (0) or 'most of the time' (1) in 72.9% (n=124/170) of patients.

9.2.2.1 Personal Anxiety (Newly Diagnosed Patients)

Personal anxiety was categorised as low (0-1) and high (2-4). Differences between the lower and higher anxiety patients were examined in relation to the factors listed in Table 64. Statistical significance of any difference was assessed.

	Lower Anxiety		Higher Anxiety					
Factor	Number	Percentage	Number	Percentage	χ^2	Df	p value	Significant
Gender								
Male	39	48.8%	41	51.3%				
Female	32	39.0%	50	61.0%	1.556	1	0.268	
Age								
<65 years	16	34.8%	30	65.2%				
≥65 years	55	47.4%	61	52.6%	2.135	1	0.163	
Histology								
Clinical	17	45.9%	20	54.1%				
NSCLC	44	43.6%	57	56.4%				
SCLC	10	41.7%	14	58.3%	0.116	2	0.944	
Stage NSCLC								
1A	0	.0%	3	100.0%				
1B	8	50.0%	8	50.0%				
2A	5	45.5%	6	54.5%				
2B	4	80.0%	1	20.0%				
3A	4	25.0%	12	75.0%				
3B	16	48.5%	17	51.5%				
4	21	42.0%	29	58.0%	7.926	6	0.244	
Stage SCLC								
Limited	6	66.7%	3	33.3%				
Extensive	4	26.7%	11	73.3%	3.703	1	0.054	
Presence or absence of metastases								
None	46	47.4%	51	52.6%				
Metasases	25	38.5%	40	61.5%	1.1269	1	0.332	
Time from diagnosis to POS								
Within 3 weeks	43	38.7%	68	61.3%				
3-6 weeks	28	54.9%	23	45.1%				
6 weeks to 3 months	0	.0%	0	.0%				
3-6 months	0	.0%	0	.0%				
6-12 months	0	.0%	0	.0%				
> 12 months	0	.0%	0	.0%	na			
Performance status rated by patients								
0-1	44	51.2%	42	48.8%				
2	14	43.8%	18	56.3%				
3-4	13	29.5%	31	70.5%	5.525	2	0.63	
Diagnosis PS, assessed by doctor								
0-1	43	50.0%	43	50.0%				
2	12	26.7%	33	73.3%				
3-4	5	71.4%	2	28.6%	8.889	2	0.012	*
Active anti-cancer treatment								
Yes	48	40.7%	70	59.3%				
No	13	54.2%	11	45.8%	1.481	1	0.262	
Deprivation								
Dep Cat 1-5	35	43.2%	46	56.8%				
Dep cat 6 or 7	36	45.6%	43	54.4%	0.09	1	0.784	
Satisfaction score								
0-4	36	47.4%	40	52.6%				
5-8	1	50.0%	1	50.0%				
9-12	0	.0%	0	.0%	na			
GP attendance between clinics								
No	25	52.1%	23	47.9%				
Yes	17	39.5%	26	60.5%	1.437	1	0.231	
Dysnoea								
No	15	51.7%	14	48.3%				
Yes	56	42.1%	77	57.9%	0.90	1.00	0.410	
Cough								
No	20	55.6%	16	44.4%				
Yes	50	40.0%	75	60.0%	2.75	1.00	0.127	
Haemoptysis								
No	60	45.8%	71	54.2%				
Yes	10	33.3%	20	66.7%	1.54	1.00	0.229	
Dysnoea								
Lower	42	53.2%	37	46.8%				
Higher	29	34.9%	54	65.1%	5.46	1.00	0.026	*
Cough								
Lower	54	53.5%	47	46.5%				
Higher	16	26.7%	44	73.3%	11.00	1.00	0.001	**
Haemoptysis								
Lower	66	45.2%	80	54.8%				
Higher	4	26.7%	11	73.3%	1.90	1.00	0.274	
Pain								
Lower	49	52.7%	44	47.3%				
Higher	22	31.9%	47	68.1%	6.96	1.00	0.010	*
Other symptoms								
Lower	65	49.2%	67	50.8%				
Higher	6	20.7%	23	79.3%	7.86	1.00	0.007	**
Support network anxiety								
Lower	34	89.5%	4	10.5%				
Higher	36	29.3%	87	70.7%	42.82	1.00	<0.001	***
Less ability to share								
Lower	57	47.1%	64	52.9%				
Higher	12	32.4%	25	67.6%	2.48	1.00	0.132	
Reduced life-worth								
Lower	62	47.7%	68	52.3%				
Higher	4	18.2%	18	81.8%	6.67	1.00	0.011	**
Reduced self-esteem								
Lower	56	53.8%	48	46.2%				
Higher	12	23.5%	39	76.5%	12.77	1.00	0.001	**
Information needs								
Lower	53	46.9%	60	53.1%				
Higher	13	34.2%	25	65.8%	1.86	1.00	0.190	
Practical needs								
Lower	51	47.7%	56	52.3%				
Higher	15	33.3%	30	66.7%	2.65	1.00	0.111	
Time wasted								
Lower	65	44.5%	81	55.5%				
Higher	1	20.0%	4	80.0%	1.18	1.00	0.387	

Table 64: Newly diagnosed patients attending the lung cancer clinic. Univariate analysis of factors across groups of higher and lower anxiety. Percentages adjusted for missing data. *p<0.05, **p<0.01 and ***p<0.001

The significant factors identified by univariate analysis were younger age, time from diagnosis, doctor-rated PS at diagnosis, dyspnoea, cough, pain, 'other' symptoms, perceived anxiety in support network, reduced life-worth and low self-esteem. In addition to these factors, gender and presence of metastases were entered into a backwards logistic regression model. The initial model included the factor of perceived anxiety in the support network, and this was the strongest contributor to the model's predictive power. As this perception may have been driven by personal anxiety, the model was repeated excluding this factor. The results of both models are tabulated below in Table 65 and Table 66.

							95% CI for Odds Ratios	
	b	SE	Wald	df	p value	Odds Ratio	Lower	Upper
Performance status 0-1 (doctor rated)			4.849	2	.089			
Performance status 2 (doctor rated)	.612	.476	1.656	1	.198	1.844	.726	4.684
Performance Status 3-4 (doctor ratec	-2.377	1.467	2.624	1	.105	.093	.005	1.647
Family anxiety (higher)	2.488	.589	17.849	1	<0.001	12.042	3.796	38.198
Reduced life-worth	2.338	1.117	4.383	1	.036	10.363	1.161	92.500
Constant	-2.023	.558	13.153	1	<0.001	.132		

R^2=0.308 (Cox and Snell); 0.413 (Nagelkerke) Model X^2=47.549, df=4, p<0.001
Hosmer-Lemeshow test: X^2=3.642, df=3, p=0.457

Table 65: Independent factors associated with higher personal anxiety identified through backwards logistic regression for newly diagnosed patients.

A test of the full model against constant only model was statistically significant (model X^2=47.549, df=4, p<0.001). Nagelkerke's R^2 of 0.413 indicated that around 41% of variance was explained by the model. Overall prediction success was 76% (52.6% for lower anxiety and 94.4% for higher anxiety). This compares to the null model overall prediction success of 55.8%. Each of the predictors in the final model was significant at the p<0.05 level. As such, higher levels of personal anxiety in newly diagnosed patients attending the lung cancer clinic were independently associated with PS at diagnosis (doctor-rated), perception of increased support network anxiety and reduced life-worth. There were no significant effects from the other variables, which were excluded from the final model. For a fixed PS and level of life-worth, patients who perceived increased anxiety in their support network were 12.042 (95% CI 3.796-38.198) times more likely to have higher levels of personal anxiety (i.e. anxiety which is moderate to overwhelming).

The regression was repeated without including the factor of perceived support network anxiety.

	b	SE	Wald	df	p value	Odds Ratio	Lower	Upper
Cough (higher)	.965	.385	6.273	1	.012	2.625	1.233	5.584
Low self-esteem	1.182	.396	8.902	1	.003	3.261	1.500	7.090
Constant	-.415	.232	3.192	1	.074	.661		

R^2=0.121 (Cox and Snell); 0.163 (Nagelkerke) Model X^2=19.46, df=2, p<0.001
Hosmer-Lemeshow test: X^2=0.403, df=2, p=0.817

Table 66: Independent factors associated with higher personal anxiety identified through backwards logistic regression for newly diagnosed patients, excluding perceived support network anxiety.

A test of the full model against constant only model was statistically significant (model X^2=19.46, df=2, p<0.001). Nagelkerke's R^2 of 0.286 indicated that around 29% of variance was explained by the model. Overall prediction success was 65.3(64.6% for lower anxiety and 65.9% for higher anxiety). This compares to the null model overall prediction success of 56.7%. Each of the predictors in the final model was significant at the p<0.05 level. As such, higher levels of personal anxiety in newly diagnosed patients attending the lung cancer clinic were independently associated with higher cough and lower self-esteem. There were no significant effects from the other variables, which were excluded from the final model. For a fixed level of cough, patients with lower self-esteem were 3.261 (95% CI 1.5-7.090) times more likely to have higher levels of personal anxiety.

9.2.2.2 Anxiety Perceived in the Support Network (Newly Diagnosed Patients)

Anxiety perceived by the patient in their support group was categorised as low (never anxious to sometimes anxious) and high (most of the time to preoccupied). The analysis was repeated to assess differences between these categories (Table 67).

	Lower Anxiety		Higher Anxiety					
Factor	Number	Percentage	Number	Percentage	χ^2	Df	p value	Significant
Gender								
Male	21	26.3%	59	73.8%				
Female	17	21.0%	64	79.0%	0.618	1	0.463	
Age								
<65 years	7	15.2%	39	84.8%				
≥65 years	31	27.0%	84	73.0%	2.511	1	0.15	
Histology								
Clinical	14	37.8%	23	62.2%				
NSCLC	19	19.0%	81	81.0%				
SCLC	5	20.8%	19	79.2%	5.435	2	0.066	
Stage NSCLC								
1A	1	33.3%	2	66.7%				
1B	4	25.0%	12	75.0%				
2A	3	27.3%	8	72.7%				
2B	2	40.0%	3	60.0%				
3A	5	31.3%	11	68.7%				
3B	8	25.0%	24	75.0%				
4	8	16.0%	42	84.0%	3.18	6	0.786	
Stage SCLC								
Limited	3	33.3%	6	66.7%				
Extensive	2	13.3%	13	86.7%	1.364	1	0.326	
Presence or absence of metastases								
None	28	29.2%	68	70.8%				
Metasases	10	15.4%	55	84.6%	4.083	1	0.058	
Time from diagnosis to POS								
Within 3 weeks	19	17.3%	91	82.7%				
3-6 weeks	19	37.3%	32	62.7%				
6 weeks to 3 months	0	.0%	0	.0%				
3-6 months	0	.0%	0	.0%				
6-12 months	0	.0%	0	.0%				
> 12 months	0	.0%	0	.0%	na			
Performance status rated by patients								
0-1	27	31.4%	59	68.6%				
2	6	18.8%	26	81.3%				
3-4	5	11.6%	38	88.4%	6.734	2	0.034	**
Diagnosis PS, assessed by doctor								
0-1	25	29.1%	61	70.9%				
2	6	13.3%	39	86.7%				
3-4	3	42.9%	4	57.1%	5.285	2	0.063	
Active anti-cancer treatment								
Yes	23	19.7%	94	80.3%				
No	9	37.5%	15	62.5%	3.613	1	0.066	
Deprivation								
Dep Cat 1-5	15	18.8%	65	81.3%				
Dep cat 6 or 7	23	29.1%	56	70.9%	2.347	1	0.14	
Albumin at diagnosis								
<35	14	24.1%	44	75.9%				
≥35	22	22.9%	74	77.1%	0.03	1	0.847	
CRP at diagnosis								
<10	19	28.8%	47	71.2%				
≥10	19	20.0%	76	80.0%	1.668	1	0.257	
Glasgow Prognostic Score								
CRP <10 and Albumin >35	15	27.8%	39	72.2%				
CRP >10 or Albumin <35	9	18.8%	39	81.3%				
CRP >10 and Albumin <35	12	24.0%	38	76.0%	1.15	2	0.563	
Satisfaction score								
0-4	20	26.3%	56	73.7%				
5-8	0	.0%	2	100.0%				
9-12	0	.0%	0	.0%	0.708	2	na	
GP attendance between clinics								
No	13	27.1%	35	72.9%				
Yes	9	21.4%	33	78.6%	0.388	1	0.626	
Dysnoea								
No	10	34.5%	19	65.5%				
Yes	28	21.2%	104	78.8%	2.32	1.00	0.149	
Cough								
No	12	33.3%	24	66.7%				
Yes	26	20.8%	99	79.2%	2.44	1.00	0.125	
Haemoptysis								
No	34	26.0%	97	74.0%				
Yes	3	10.3%	26	89.7%	3.25	1.00	0.089	
Dysnoea								
Lower	24	30.8%	54	69.2%				
Higher	14	16.9%	69	83.1%	4.31	1.00	0.043	*
Cough								
Lower	32	31.7%	69	68.3%				
Higher	6	10.0%	54	90.0%	9.81	1.00	0.002	**
Haemoptysis								
Lower	37	25.3%	109	74.7%				
Higher	0	.0%	14	100.0%	4.62	1.00	0.041	*
Pain								
Lower	30	32.6%	62	67.4%				
Higher	8	11.6%	61	88.4%	9.66	1.00	0.002	**
Other symptoms								
Lower	35	26.7%	96	73.3%				
Higher	3	10.3%	26	89.7%	3.52	1.00	0.089	
Personal anxiety								
Lower	34	48.6%	36	51.4%				
Higher	4	4.4%	87	95.6%	42.82	1.00	<0.001	***
Less ability to share								
Lower	29	24.2%	91	75.8%				
Higher	7	18.9%	30	81.1%	0.44	1.00	0.656	
Reduced life-worth								
Lower	33	25.6%	96	74.4%				
Higher	1	4.5%	21	95.5%	4.77	1.00	0.028	**
Reduced self-esteem								
Lower	31	30.1%	72	69.9%				
Higher	4	7.8%	47	92.2%	9.62	1.00	0.002	**
Information needs								
Lower	29	25.9%	83	74.1%				
Higher	5	13.2%	33	86.8%	2.53	1.00	0.121	
Practical needs								
Lower	29	27.1%	78	72.9%				
Higher	5	11.4%	39	88.6%	4.43	1.00	0.052	
Time wasted								
Lower	33	22.8%	112	77.2%				
Higher	1	20.0%	4	80.0%	0.21	1.00	1.000	

Table 67: Newly diagnosed patients attending the lung cancer clinic. Univariate analysis of factors across groups of higher and lower perceived support network anxiety. Percentages adjusted for missing data. *p<0.05, **p<0.01 and ***p<0.001

The significant factors identified by univariate analysis were time from diagnosis, PS, dyspnoea, cough, haemoptysis, pain, personal anxiety, reduced life-worth and low self-esteem. In addition to these factors, gender and presence of metastases were entered into a backwards logistic regression model. Initial modelling containing degree of haemoptysis could not be achieved due to the large standard error resulting from only a few 'higher' haemoptysis cases being present. Therefore, the model was repeated with presence or absence of haemoptysis as the variable entered. The initial model included the factor of personal anxiety, and the model was repeated excluding this factor. The results of both models are tabulated below in Table 68 and Table 69.

							95% CI for Odds Ratios	
	b	SE	Wald	df	p value	Odds Ratio	Lower	Upper
Pain (higher)	1.118	.512	4.762	1	.029	3.057	1.121	8.341
Personal anxiety (higher)	2.774	.576	23.219	1	<0.001	16.016	5.183	49.489
Constant	-.188	.294	.406	1	.524	.829		

R^2=0.254 (Cox and Snell); 0.387 (Nagelkerke) Model X^2=44.151, df=2, p<0.001
Hosmer-Lemeshow test: X^2=0.006, df=2, p=0.997

Table 68: Independent factors associated with higher support network anxiety identified through backwards logistic regression for newly diagnosed patients.

A test of the full model against constant only model was statistically significant (model X^2=44.151, df=2, p<0.001). Nagelkerke's R^2 of 0.417 indicated that around 42% of variance was explained by the model. Overall prediction success was 80.1 (70.6% for lower anxiety and 82.9% for higher anxiety). This compares to the null model overall prediction success of 77.5%. Each of the predictors in the final model was significant at the p<0.05 level. As such, higher levels of perceived anxiety in the support network in newly diagnosed patients were independently associated with increased pain and increased personal anxiety. There were no significant effects from the other variables, which were excluded from the final model. For a fixed level of pain, patients who rated higher personal anxiety were 16.016 (95% CI 5.183-49.489) times more likely to perceive higher levels of anxiety in their support group (i.e. anxiety which is moderate to overwhelming).

	b	SE	Wald	df	p value	Odds Ratio	Lower	Upper
Cough (higher)	1.169	.538	4.723	1	.030	3.219	1.122	9.238
Pain (higher)	1.047	.482	4.712	1	.030	2.850	1.107	7.337
Low self-esteem	1.281	.584	4.814	1	.028	3.600	1.146	11.307
Constant	.266	.272	.955	1	.328	1.305		

R^2=0.140 (Cox and Snell); 0.213 (Nagelkerke) Model X^2=22.693, df=3, p<0.001
Hosmer-Lemeshow test: X^2=5.204, df=6, p=0.518

Table 69: Independent factors associated with higher support network anxiety identified through backwards logistic regression for newly diagnosed patients. Personal anxiety excluded.

A test of the full model against constant only model was statistically significant (model X^2=22.69, df=3, p<0.001). Nagelkerke's R^2 of 0.213 indicated that around 21% of variance was explained by the model. Overall prediction success was 77.5% (0% for lower anxiety and 100% for higher anxiety). This compares to the null model overall prediction success of 77.5%. Each of the predictors in the final model was significant at the p<0.05 level. As such, higher levels of perceived anxiety in the support network of newly diagnosed patients were independently associated with higher cough, higher pain and reduced self-esteem. There were no significant effects from the other variables, which were excluded from the final model. For a fixed level of cough and pain, patients with reduced self-esteem were 3.6 (95% CI 1.46-11.307) times more likely to perceive higher levels of anxiety in their support group.

9.2.3 Anxiety in Patients in the Last Three Months of Life

Personal anxiety felt (mean 1.79, median 1, range 0-4, SD 1.34) was reported to be low (0-1) in 41.3% (n=50/121) of patients within the last three months of life. Higher anxiety levels (2-4) were described by 51.2% (n=63/121) of patients. Anxiety perceived in the support network (mean 2.40, SD 1.35, median 3, range 0-4) was reported to be low (0-1) by 43.0% (n=52/121) of patients and described as high (2-4) by 52.1% (n=62/121). Being able to share feelings (mean 0.91, SD 1.23, median 0, range 0-4) was reported to be felt possible 'as much as I want' (0) or 'most of the time' (1) in 68.6% (n=83/170) of patients.

9.2.3.1 Personal Anxiety (Patients in the Last Three Months of Life)

Personal anxiety was categorised as low (0-1) and high (2-4). Differences between the lower and higher anxiety patients were examined in relation to the factors listed in Table 70. Statistical significance of any difference was assessed.

	Lower Anxiety		Higher Anxiety					
Factor	Number	Percentage	Number	Percentage	χ^2	Df	p value	Significant
Gender								
Male	27	45.0%	33	55.0%				
Female	23	43.4%	30	56.6%	0.03	1	1.000	
Age								
<65 years	10	35.7%	18	64.3%				
≥65 years	40	47.1%	45	52.9%	1.10	1	0.381	
Histology								
Clinical	9	56.3%	7	43.8%				
NSCLC	32	42.1%	44	57.9%				
SCLC	9	42.9%	12	57.1%	1.09	2	0.579	
Stage NSCLC								
1A	0	.0%	1	100.0%				
1B	3	42.9%	4	57.1%				
2A	5	83.3%	1	16.7%				
2B	1	50.0%	1	50.0%				
3A	4	66.7%	2	33.3%				
3B	10	35.7%	18	64.3%				
4	17	41.5%	24	58.5%	6.73	6	0.347	
Stage SCLC								
Limited	2	33.3%	4	66.7%				
Extensive	7	46.7%	8	53.3%	0.31	1	0.577	
Presence or absence of metastases								
None	26	45.6%	31	54.4%				
Metasases	24	42.9%	32	57.1%	0.87	1	0.850	
Time from diagnosis to POS								
Within 3 weeks	7	25.0%	21	75.0%				
3-6 weeks	3	50.0%	3	50.0%				
6 weeks to 3 months	10	55.6%	8	44.4%				
3-6 months	8	47.1%	9	52.9%				
6-12 months	13	52.0%	12	48.0%				
> 12 months	9	47.4%	10	52.6%	5.96	5	0.310	
Performance status rated by patients								
0-1	19	59.4%	13	40.6%				
2	10	34.5%	19	65.5%				
3-4	21	40.4%	31	59.6%	4.40	2	0.111	
Diagnosis PS, assessed by doctor								
0-1	27	45.0%	33	55.0%				
2	16	43.2%	21	56.8%				
3-4	5	71.4%	2	28.6%	1.96	2	0.370	
Active anti-cancer treatment								
Yes	34	41.5%	48	58.5%				
No	12	60.0%	8	40.0%	2.23	1	0.210	
Deprivation								
Dep Cat 1-5	25	42.4%	34	57.6%				
Dep cat 6 or 7	25	46.3%	29	53.7%	0.18	1	0.708	
Satisfaction score								
0-4	25	47.2%	28	52.8%				
5-8	1	100.0%	0	.0%				
9-12	0	.0%	0	.0%	na			
GP attendance between clinics								
No	10	45.5%	12	54.5%				
Yes	17	44.7%	21	55.3%	0.00	1	1.000	
Dysnoea								
No	12	66.7%	6	33.3%				
Yes	38	40.0%	57	60.0%	4.36	1	0.042	*
Cough								
No	15	46.9%	17	53.1%				
Yes	35	43.2%	46	56.8%	0.13	1	0.834	
Haemoptysis								
No	44	46.8%	50	53.2%				
Yes	6	31.6%	13	68.4%	1.49	1	0.312	
Dysnoea								
Lower	23	57.5%	17	42.5%				
Higher	27	37.0%	46	63.0%	4.41	1	0.048	*
Cough								
Lower	35	55.6%	28	44.4%				
Higher	15	30.0%	35	70.0%	7.38	1	0.008	**
Haemoptysis								
Lower	47	44.3%	59	55.7%				
Higher	3	42.9%	4	57.1%	0.01	1	1.000	
Pain								
Lower	26	55.3%	21	44.7%				
Higher	24	36.4%	42	63.6%	4.00	1	0.056	
Other symptoms								
Lower	38	51.4%	36	48.6%				
Higher	12	30.8%	27	69.2%	4.39	1	0.470	
Support network anxiety								
Lower	27	90.0%	3	10.0%				
Higher	23	27.7%	60	72.3%	34.66	1	<0.001	***
Less ability to share								
Lower	36	45.0%	44	55.0%				
Higher	13	40.6%	19	59.4%	0.18	1	0.833	
Reduced life-worth								
Lower	45	50.0%	45	50.0%				
Higher	4	19.0%	17	81.0%	6.62	1	0.014	*
Reduced self-esteem								
Lower	40	59.7%	27	40.3%				
Higher	9	20.0%	36	80.0%	17.24	1	<0.001	***
Information needs								
Lower	38	46.9%	43	53.1%				
Higher	10	33.3%	20	66.7%	1.65	1	0.281	
Practical needs								
Lower	39	49.4%	40	50.6%				
Higher	10	31.3%	22	68.8%	3.03	1	0.095	
Time wasted								
Lower	49	45.4%	59	54.6%				
Higher	0	.0%	3	100.0%	2.44	1	0.254	

Table 70: Patients within three months of death. Univariate analysis of factors across groups of higher and lower personal anxiety. Percentages are adjusted for missing data. *p<0.05, **p<0.01 and ***p<0.001

The significant factors identified by univariate analysis were dyspnoea, cough, 'other' symptoms, perceived anxiety in support network, reduced life-worth and low self-esteem. In addition to these factors, gender, age and presence of metastases were entered into a backwards logistic regression model. The initial model included the factor of perceived anxiety in the support network, and the model was repeated excluding this factor. The results for both models are tabulated below in Table 71 and Table 72.

							95% CI for Odds Ratios	
	b	SE	Wald	df	p value	Odds Ratio	Lower	Upper
Family anxiety (higher)	2.882	.673	18.317	1	<0.001	17.851	4.769	66.812
Low self-esteem	1.362	.509	7.174	1	.007	3.904	1.441	10.577
Constant	-2.478	.637	15.136	1	<0.001	.084		

R^2=0.338 (Cox and Snell); 0.453 (Nagelkerke) Model X^2=45.773, df=2, p<0.001
Hosmer-Lemeshow test: X^2=0.000, df=2, p=1.000

Table 71: Independent factors associated with higher personal anxiety identified through backwards logistic regression for patients who died within three months.

A test of the full model against constant only model was statistically significant (model X^2=45.773, df=2, p<0.001). Nagelkerke's R^2 of 0.453 indicated that around 45% of variance was explained by the model. Overall prediction success was 77.5% (55.2% for lower anxiety and 95.2% for higher anxiety). This compares to the null model overall prediction success of 55.9%. Each of the predictors in the final model was significant at the p<0.05 level. As such, higher levels of personal anxiety in patients who died within three months were independently associated with perception of increased support network anxiety and reduced self-esteem. There were no significant effects from the other variables, which were excluded from the final model. For a fixed level of self-esteem, patients who perceived increased anxiety in their support network were 17.851 (95% CI 4.796-66.812) times more likely to have higher levels of personal anxiety (i.e. anxiety which is moderate to overwhelming).

The regression was repeated without including the factor of perceived support network anxiety.

	b	SE	Wald	df	p value	Odds Ratio	Lower	Upper
Low self-esteem	1.817	.450	16.317	1	<0.001	6.154	2.548	14.861
Constant	-.431	.252	2.924	1	.087	.650		

R^2=0.156 (Cox and Snell); 0.209 (Nagelkerke) Model X^2=18.813, df=1, p<0.001
Hosmer-Lemeshow test: X^2=0.000, df=0

Table 72: Independent factors associated with higher personal anxiety identified through backwards logistic regression for patients who died within three months, excluding perceived support network anxiety.

A test of the full model against constant only model was statistically significant (model X^2=18.813, df=1, p<0.001). Nagelkerke's R^2 of 0.286 indicated that around 29% of

variance was explained by the model. Overall prediction success was 68.5 (81.6% for lower anxiety and 58.1% for higher anxiety). This compares to the null model overall prediction success of 56.7%. Each of the predictors in the final model was significant at the $p<0.05$ level. As such, higher levels of personal anxiety in patients who died within three months were independently associated with reduced self-esteem. There were no significant effects from the other variables which were excluded from the final model. Patients with lower self-esteem were 6.154 (95% CI 2.545-14.861) times more likely to have higher levels of personal anxiety.

9.2.3.2 Anxiety Perceived in the Support Network (Patients in the Last Three Months of Life)

Anxiety perceived by the patient in their support group was categorised as low (never anxious to sometimes anxious) and high (most of the time to preoccupied). The analysis was repeated to assess differences between these categories (Table 73).

	Lower Anxiety		Higher Anxiety					
Factor	Number	Percentage	Number	Percentage	χ^2	Df	p value	Significant
Gender								
Male	17	27.9%	44	72.1%				
Female	14	26.4%	39	73.6%	0.3	1	1	
Age								
<65 years	8	28.6%	20	71.4%				
≥65 years	23	26.7%	63	73.3%	0.36	1	1	
Histology								
Clinical	6	35.3%	11	64.7%				
NSCLC	18	23.7%	58	76.3%				
SCLC	7	33.3%	14	66.7%	1.436	2	0.488	
Stage NSCLC								
1A	0	.0%	1	100.0%				
1B	2	28.6%	5	71.4%				
2A	1	16.7%	5	83.3%				
2B	1	50.0%	1	50.0%				
3A	2	33.3%	4	66.7%				
3B	7	24.1%	22	75.9%				
4	10	24.4%	31	75.6%	1.512	6	0.959	
Stage SCLC								
Limited	1	16.7%	5	83.3%				
Extensive	6	40.0%	9	60.0%	1.05	1	0.306	
Presence or absence of metastases								
None	15	25.9%	43	74.1%				
Metasases	16	28.6%	40	71.4%	0.106	1	0.834	
Time from diagnosis to POS								
Within 3 weeks	3	10.7%	25	89.3%				
3-6 weeks	3	50.0%	3	50.0%				
6 weeks to 3 months	5	27.8%	13	72.2%				
3-6 months	6	33.3%	12	66.7%				
6-12 months	6	24.0%	19	76.0%				
> 12 months	8	42.1%	11	57.9%	8.025	5	0.155	
Performance status rated by patients								
0-1	15	45.5%	18	54.5%				
2	5	17.2%	24	82.8%				
3-4	11	21.2%	41	78.8%	7.967	2	0.019	*
Diagnosis PS, assessed by doctor								
0-1	16	26.7%	44	73.3%				
2	11	28.9%	27	71.1%				
3-4	4	57.1%	3	42.9%	2.808	2	0.246	
Active anti-cancer treatment								
Yes	21	25.3%	62	74.7%				
No	7	35.0%	13	65.0%	0.766	1	0.408	
Deprivation								
Dep Cat 1-5	14	23.3%	46	76.7%				
Dep cat 6 or 7	17	31.5%	37	68.5%	0.953	1	0.401	
Satisfaction score								
0-4	19	35.8%	34	64.2%				
5-8	0	.0%	1	100.0%				
9-12	0	.0%	0	.0%	na			
GP attendance between clinics								
No	8	36.4%	14	63.6%				
Yes	12	31.6%	26	68.4%	0.144	1	0.78	
Dysnoea								
No	7	38.9%	11	61.1%				
Yes	24	25.0%	72	75.0%	1.48	1.00	0.253	
Cough								
No	9	28.1%	23	71.9%				
Yes	21	25.9%	60	74.1%	0.57	1.00	0.817	
Haemoptysis								
No	26	27.7%	68	72.3%				
Yes	4	21.1%	15	78.9%	0.35	1.00	0.777	
Dysnoea								
Lower	15	36.6%	26	63.4%				
Higher	16	21.9%	57	78.1%	2.85	1.00	0.124	
Cough								
Lower	23	36.5%	40	63.5%				
Higher	7	14.0%	43	86.0%	7.24	1.00	0.010	*
Haemoptysis								
Lower	30	28.3%	76	71.7%				
Higher	0	.0%	7	100.0%	2.70	1.00	0.187	
Pain								
Lower	18	37.5%	30	62.5%				
Higher	13	19.7%	53	80.3%	4.45	1.00	0.054	
Other symptoms								
Lower	25	33.8%	49	66.2%				
Higher	5	12.8%	34	87.2%	5.58	1.00	0.024	*
Personal anxiety								
Lower	27	54.0%	23	46.0%				
Higher	3	4.8%	60	95.2%	34.66	1.00	<0.001	***
Less ability to share								
Lower	24	29.6%	57	70.4%				
Higher	7	21.9%	25	78.1%	0.69	1.00	0.487	
Reduced life-worth								
Lower	27	29.7%	64	70.3%				
Higher	4	19.0%	17	81.0%	0.96	1.00	0.423	
Reduced self-esteem								
Lower	27	39.7%	41	60.3%				
Higher	4	8.9%	41	91.1%	12.92	1.00	<0.001	***
Information needs								
Lower	28	34.1%	54	65.9%				
Higher	2	6.7%	28	93.3%	8.46	1.00	0.003	**
Practical needs								
Lower	22	27.5%	58	72.5%				
Higher	9	28.1%	23	71.9%	0.00	1.00	1.000	
Time wasted								
Lower	31	28.4%	78	71.6%				
Higher	0	.0%	3	100.0%	1.18	1.00	0.559	

Table 73: Patients within three months of death. Univariate analysis of factors across groups of higher and lower perceived support network anxiety. Percentages adjusted for missing data. *p<0.05, **p<0.01 and ***p<0.001

The significant factors identified by univariate analysis were PS, cough, 'other' symptoms, personal anxiety, low self-esteem and information needs. In addition to these factors, gender and presence of metastases were entered into a backwards logistic regression model. The initial model included the factor of personal anxiety, and the model was repeated excluding this factor. The results of both models are tabulated below (Table 74 and Table 75).

							95% CI for Odds Ratios	
	b	SE	Wald	df	p value	Odds Ratio	Lower	Upper
Personal anxiety (higher)	3.215	.676	22.594	1	<0.001	24.898	6.614	93.724
Information needs (higher)	2.060	.834	6.109	1	.013	7.848	1.532	40.204
Constant	-.559	.334	2.796	1	.095	.572		

R^2=0.335 (Cox and Snell); 0.491 (Nagelkerke) Model X^2=45.333, df=2, p<0.001
Hosmer-Lemeshow test: X^2=0.216, df=2, p=0.898

Table 74: Independent factors associated with higher support network anxiety identified through backwards logistic regression for patients who died within three months.

A test of the full model against constant only model was statistically significant (model X^2=45.333, df=2, p<0.001). Nagelkerke's R^2 of 0.491 indicated that around 49% of variance was explained by the model. Overall prediction success was 82.9% (82.8% for lower anxiety and 82.9% for higher anxiety). This compares to the null model overall prediction success of 73.9%. Each of the predictors in the final model was significant at the p<0.05 level. As such, higher levels of perceived anxiety in the support network in patients who died within three months were independently associated with increased personal anxiety and increased information needs. There were no significant effects from the other variables which were excluded from the final model. For a fixed level of information need, patients who rate higher personal anxiety were 24.898 (95% CI 6.614-93.724) times more likely to perceive higher levels of anxiety in their support group (i.e. anxiety which is moderate to overwhelming).

	b	SE	Wald	df	p value	Odds Ratio	Lower	Upper
Other symptoms (higher)	1.097	.578	3.604	1	.058	2.996	.965	9.303
Low self-esteem	1.575	.605	6.787	1	.009	4.833	1.477	15.812
Information needs (higher)	1.901	.793	5.741	1	.017	6.692	1.413	31.691
Constant	-.074	.311	.057	1	.811	.928		

R^2=0.198 (Cox and Snell); 0.290 (Nagelkerke) Model X^2=24.464, df=3, p<0.001
Hosmer-Lemeshow test: X^2=9.095, df=4, p=0.059

Table 75: Independent factors associated with higher support network anxiety identified through backwards logistic regression for patients who died within three months. Personal anxiety was excluded.

A test of the full model against constant only model was statistically significant (model X^2=24.464, df=3, p<0.001). Nagelkerke's R^2 of 0.213 indicated that around 21% of variance was explained by the model. Overall prediction success was 79.3% (75.9% for

lower anxiety and 80.5% for higher anxiety). This compares to the null model overall prediction success of 73.9%. Each of the predictors in the final model was significant at the $p<0.05$ level. As such, higher levels of perceived anxiety in the support network of patients within three months of death were independently associated with increased information needs, 'other' symptoms and reduced self-esteem. There were no significant effects from the other variables which were excluded from the final model. For a fixed level of information need and 'other'symptoms, patients with reduced self-esteem were 4.833 (95% CI 1.477-16.812) times more likely to perceive higher levels of anxiety in their support group.

9.3 Discussion

The current study demonstrates the high prevalence within the Stobhill lung cancer clinic of anxiety in both patients themselves and as perceived in the support network. There is a strong relationship between these factors. Furthermore, reduced self-esteem is a strong predictor of increased anxiety. Other physical and psychosocial factors contribute at different stages within the lung cancer journey.

Anxiety is a common and normal response to a diagnosis of cancer.[342] It can become maladaptive for some patients, impacting on quality of life, function and symptom burden. Maladaptive anxiety is characterised as being persistent, intrusive and disproportionate to the stimulus. Assessing anxiety within the context of a real and persistent but dynamic threat such as cancer is a challenge.[2, 342, 350, 370-372]

Lung cancer is a serious diagnosis that often heralds high symptom burden, decline in physical health and short survival. Patients diagnosed with lung cancer may not have their supportive care needs fully identified or met.[12, 104, 157, 281, 379] It has been recognised that patients deal with illness in the context of a social environment and that this may positively or negatively influence their ability to cope.[302, 378]

The concept of symptom distress, encompassing symptom occurrence, intensity and impact on patients, is gaining ground.[121] Congruence between patient perception of symptom distress and that of their support network or professional carers may also influence their ability to cope with and discuss their illness.[164, 169]

9.3.1 Anxiety

This study confirms that anxiety is a significant issue within the lung cancer population. Around 46% of patients within the lung cancer clinic experienced moderate to overwhelming personal anxiety. Over half of these patients felt anxious about their illness 'most of the time' or were 'completely preoccupied'. This is consistent with findings of moderate to overwhelming anxiety ranging between 10-45% in other lung cancer studies.[342, 379, 380] Sanders et al[216] found that around 50% of lung cancer patients reported anxiety as a troubling issue. Furthermore, they identified that half of the patients were interested in receiving psychological support through at least one service. Steinberg et al[160] described that 22% of newly diagnosed lung cancer patients experience 'nervousness' as part of clinically relevant 'distress'. In the current study, anxiety was a significant issue from the point of diagnosis until the end of life. Personal anxiety was more prevalent in the newly diagnosed patients and in those within the last three months of life than in the general clinic population. Fifty three percent of newly diagnosed patients reported moderate to overwhelming anxiety and 52.1% of patients reported the same within the last three months of life. This is in keeping with the qualitative study by Murray et al[180] which identified peaks of psychological distress at diagnosis, discharge and points of recurrence or progression in lung cancer. Particular attention should be given to these identified junctures in the lung cancer journey to ensure that suitable support is provided for those with distressing personal anxiety.

The affects of anxiety and depression on quality of life at the time of diagnosis have also been described by Montazeri et al.[342] They describe potential anxiety issues identified by the Hospital Anxiety and Depression Scale in 6% of lung cancer patients during the investigation phase; this increased to 11% at follow-up later in their illness. Depression was potentially an issue in 11% at diagnosis, increasing to 22% at follow-up. The authors also noted that global quality of life (measured by EORTC QLQ-C30) was significantly reduced in those with increased anxiety or depression. In the current study, time from diagnosis (i.e. greater versus less than six months from diagnosis) was a significant factor in predicting higher personal anxiety; those surviving greater than six months were less likely to express higher personal anxiety.

9.3.2 Anxiety, Age, Gender, Stage, Deprivation and Histology

Anxiety in lung cancer patients has been previously described to be higher in females, younger patients and those with more advanced stage disease.[2] However, these findings

have not been consistently described, and opposing findings have also been reported.[2] In the current study, no relationship was found between either personal anxiety or perceived support network anxiety and gender. In univariate analysis, younger age was found to be associated with higher personal anxiety and higher perceived support network anxiety in the general clinic population and in newly diagnosed patients. Using logistic regression, age was not a significant independent predictor of anxiety in any of the clinical groupings. Previous studies have found increased distress relating to stage of disease, whereas others reported no difference across stage of disease.[2] Given the likely dynamic nature of anxiety in lung cancer,[180] it is possible to understand how conflicting results can arise.

In the current study, no relationship was found between the presence of metastatic disease and personal anxiety (using both univariate and multivariate analyses). The presence of metastases did influence the perception of higher support network anxiety in the general clinic population but not at diagnosis or at the end of life. Histology was not a significant factor in any of the analyses. Deprivation level also did not influence anxiety levels.

9.3.3 Personal Anxiety and Perceived Support Network Anxiety

As a patient's own anxiety increased, they also perceived increased anxiety within their own support network.[381] It is of note that patients in this study perceived higher levels of anxiety in their support network than the level of personal anxiety they described. Previous studies utilising POS have also found this to be the case.[147, 218-220] The perception of increased anxiety within the support network was the strongest predictor of higher personal anxiety in each of the clinical groupings (Table 59, Table 65 and Table 71). A reciprocal relationship was observed, with personal anxiety being the strongest predictor of increased support network anxiety (Table 62, Table 68 and Table 74). This congruence of psycho-emotional response may influence the support felt by the patient and their willingness to discuss their illness or feelings.[382]

In their review article, Pitceathly and Macguire[383] outlined the reasons for increased distress in carers and noted a well-documented correlation between the psychological adjustment of couples irrespective of cancer type or stage. This relationship held true whether or not the significant other was a spouse. It could be hypothesised that patients

who feel support network anxiety that mirrors their personal anxiety demonstrate recognition and understanding. Other patients may wish to withhold their own worries in an attempt to protect the significant other.[384]

A patient's support network is important in aiding them to cope and face their cancer diagnosis.[12, 384] The concept of caring for the support network has been tested for feasibility[348, 377] and purpose in the lung cancer setting.[385] In the current study, the majority of patients felt that they were able to share how they were feeling as much as they wanted or most of the time, irrespective of the phase of lung cancer journey. However, a sizable minority of patients (10.2%) felt only occasionally able to share or not able to share at all. Reduced ability to share was associated with higher personal anxiety and support network anxiety in univariate analysis in the general clinic. Increased psychosocial distress may be associated with reduced support or social functioning in lung cancer.[2] In the current study, eight patients in the general clinic population described higher anxiety and also felt unable to share their feelings with anyone at all. Although this is a relatively small number of patients, it is important to identify psychosocial distress in individuals who have such low levels of support. Early identification of patients with low levels of perceived support may be important to allow targeted supportive care measures to meet this deficit in a timely fashion. This may help prevent the development of psychosocial distress or aid the treatment of anxiety or other psychological issues.

9.3.4 Anxiety and Self-Worth

The univariate analyses of personal anxiety (Table 58, Table 64 and Table 70) in each clinical grouping confirm previous studies (including a published interim analysis from the current study;[381] see Appendix 9) that there is a strong relationship between anxiety and depression or reduced self-worth ('have you felt your life-worthwhile?' and 'have you felt good about yourself?').[379, 381, 386] This relationship is observed for perceived anxiety in the support network for both reduced self-worth and reduced life-worth in each clinical grouping except the last three months of life group (reduced life-worth not significant). Logistic regression identified low self-esteem ('have you felt good about yourself?') as a major predictor of high personal anxiety and increased perceived anxiety in the support network in each of the clinical groupings.

Self-esteem can be defined as 'the degree to which an individual holds attitudes of acceptance or rejection towards themselves'.[387] There is a well documented relationship between anxiety and self-esteem in non-cancer and general population studies.[387-389] The relationship between self-esteem and anxiety in the cancer setting has also been explored.[390, 391] In both cancer and non-cancer settings, it remains unclear whether low self-esteem leads to increased anxiety or whether increased anxiety leads to reduced self-worth.[387] However, both anxiety and reduced self-esteem can be addressed through well-established psychotherapeutic methods.[371, 392] Thus, given the strong relationship identified between anxiety and reduced self-esteem in the current study, identification of either problem should prompt further evaluation to assess the presence of the second unmet need.

9.3.5 Anxiety, Symptoms and Performance Status

Increased patient anxiety has been described in advanced cancer when symptom burden is high.[2] Univariate analysis confirmed this for specific physical symptoms of dyspnoea, cough, haemoptysis, pain and 'other' symptoms in the general clinic population (Table 58). Furthermore, worse patient-rated PS was also associated with higher personal and support network anxiety. In newly diagnosed patients, the main physical variables associated with increased anxiety were dyspnoea, cough, pain and 'other' symptoms but not patient-rated PS (Table 64). In the last three months of life, the only physical symptoms related to increased anxiety identified were dyspnoea and cough (Table 70). On logistic regression, no physical factors predicted increased personal anxiety at the end of life. In newly diagnosed patients and in the general clinic, reduced performance status and cough were the major physical contributors to the models.

Cough may be underrated by carers and healthcare workers as a cause of distress.[168, 176] In the Lobchuk et al[168] study of congruence between symptom distress rated by lung cancer patients and their carers, cough was rated as the second most distressing symptom by patients (fatigue was most distressing) but only the fourth most distressing symptom by carers (below fatigue, psychological outlook and insomnia). However, other studies have reported the opposite finding: carers and healthcare professionals rated cough as more distressing than the patient.[169] Increased support network anxiety was associated with pain and cough in newly diagnosed patients, 'other' symptoms at the end of life and haemoptysis in the general clinic population. Dyspnoea has been previously associated with anxiety in lung cancer.[355, 393] It is interesting to note that

although dyspnoea was associated with increased anxiety in univariate analysis, it was not an independent predictor in any of the regression models.

Worse PS (patient-rated) was a predictor of increased anxiety in the general clinic population when perceived anxiety was excluded from the model. Conversely, in newly diagnosed patients, worse PS (doctor-rated) was an independent predictor of lower anxiety, and patient-rated PS did not contribute to the model. It is not clear why this would be the case, although it is well-documented that PS assessment by healthcare professionals and patients differ.[103]

9.3.6 Anxiety, Survival and Active Treatment

The relationship between anxiety and cancer survival is unclear and remains controversial.[370] The effect of anxiety on survival was studied in the previous section (see Section 8). It has been reported that patients receiving no active anti-cancer treatment experience increased psychological distress.[2] In the current study, no relationship was found between active anti-cancer treatment and anxiety levels.

9.3.7 Anxiety and Information Needs

Despite the existence of clear guidelines for delivering information to lung cancer patients,[394] unmet information needs were apparent in around 30% of the general clinic population, 35% of newly diagnosed patients and 31% of patients within the last three months of life. Information needs strongly contributed to the models for prediction of both personal and support network anxiety in the last three months of life but not in the other clinical groupings. It is possible that as patients recognise physical decline and increasingly limited treatment options, their information needs gain a greater degree of importance despite the prevalence being similar to previous points within the cancer journey. Previous studies have suggested that 'truth-telling' is important to the well-being of most patients near the end of life.[395, 396]

9.4 Conclusions

The presence of anxiety is an important issue in cancer care. It may reflect recognition of advancing disease or become disproportionate to the current condition. Maladaptive anxiety can 'choke' or 'strangle' the patient's quality of life.

Within the Stobhill lung cancer service many patients report both personal anxiety and perceive high levels of worry within their support network. Most patients do perceive recognition within their support network that their condition merits increased concern when symptoms are high, personal distress is increased and at particular junctures of the lung cancer journey. The majority of patients felt able to share their worries and concerns with significant others, irrespective of their own anxiety levels.

Lung cancer care operates within a dynamic and often rapidly declining situation. The presence of high personal anxiety was strongly related to increased perceived anxiety within the support network. Personal anxiety was not readily predicted by gender, age, stage or histology. ECOG PS and some specific symptoms such as cough, pain and haemoptysis may aid assessment. Early recognition of anxiety and facilitating further support – through significant others or members of the health care team – may help relieve the stranglehold of psychological distress. Prompt assessment and response to distress within this acute illness trajectory is necessary.

10 Pain in Lung Cancer

In keeping with Aim 4c, this section evaluates the predictors of increased pain in the Stobhill lung cancer clinic population. The predictors evaluated were all readily available within the Stobhill clinical service and may serve to allow effective and efficient targeting of pain control within the service. The methodology and statistical approach are outlined in Section 3.

10.1 Introduction

Pain can be defined as 'an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such'.[397] In lung cancer, pain can result from the disease, treatments or unrelated co-morbidities.[398-401] It is a common symptom[401] and is often associated with distress[399] (see Section 1.5). The majority of pains in cancer can be controlled by identification and subsequent management utilising the analgesic ladder.[398, 402] Lung cancer patients consistently rate pain as one of their top concerns,[401] and there is some evidence that they experience more pain than patients with other types of cancer.[400, 401, 403] Furthermore, many lung cancer patients will experience mixed nociceptive-neuropathic pain[401-403] which can be more difficult to control than other types of pain.[383] In the current study, pain was identified as a significant physical problem for lung cancer patients. This troublesome symptom is further evaluated.

10.2 Results

10.2.1 Pain in All Patients Attending the Lung Cancer Clinic

Pain felt (mean 1.28, SD 1.18, median 1, range 0-4) was reported to be low (0-1) in 55.8% (n=197/353) of patients and high (2-4) in 40.1% (n=144/353) of patients. The factors tabulated below were evaluated for significant differences across lower and higher pain (Table 76).

	Lower Pain		Higher Pain					
Factor	Number	Percentage	Number	Percentage	χ^2	Df	p value	Significant
Gender								
Male	93	55.7%	74	44.3%				
Female	104	59.8%	70	40.2%	0.582	1	0.511	
Age								
<65 years	46	47.9%	50	52.1%				
≥65 years	151	61.6%	94	38.4%	5.319	1	0.028	*
Histology								
Clinical	34	53.1%	30	46.9%				
NSCLC	134	57.3%	100	42.7%				
SCLC	29	67.4%	14	32.6%	2.239	2	0.326	
Stage NSCLC								
1A	16	69.6%	7	30.4%				
1B	29	60.4%	19	39.6%				
2A	8	38.1%	13	61.9%				
2B	14	70.0%	6	30.0%				
3A	16	59.3%	11	40.7%				
3B	35	49.3%	36	50.7%				
4	45	54.9%	37	45.1%	7.864	6	0.248	
Stage SCLC								
Limited	11	73.3%	4	26.7%				
Extensive	17	65.4%	9	34.6%	0.278	1	0.598	
Presence or absence of metastases								
None	135	57.9%	98	42.1%				
Metasases	62	57.4%	46	42.6%	0.009	1	1	
Time from diagnosis to POS								
Within 3 weeks	64	56.1%	50	43.9%				
3-6 weeks	29	55.8%	23	44.2%				
6 weeks to 3 months	21	65.6%	11	34.4%				
3-6 months	24	58.5%	17	41.5%				
6-12 months	22	57.9%	16	42.1%				
> 12 months	34	55.7%	27	44.3%	1.11	5	0.953	
Performance status rated by patients								
0-1	129	71.7%	51	28.3%				
2	31	45.6%	37	54.4%				
3-4	37	39.8%	56	60.2%	30.716	2	<0.001	***
Diagnosis PS, assessed by doctor								
0-1	131	61.8%	81	38.2%				
2	45	57.0%	34	43.0%				
3-4	5	55.6%	4	44.4%	0.65	2	0.723	
Active anti-cancer treatment								
Yes	153	57.5%	113	42.5%				
No	28	60.9%	18	39.1%	0.181	1	0.747	
Deprivation								
Dep Cat 1-5	90	58.1%	65	41.9%				
Dep cat 6 or 7	106	58.9%	74	41.1%	0.023	1	0.912	
Satisfaction score								
0-4	71	55.5%	57	44.5%				
5-8	0	.0%	3	100.0%				
9-12	0	.0%	0	.0%	na			
GP attendance between clinics								
No	46	60.5%	30	39.5%				
Yes	36	48.0%	39	52.0%	2.387	1	0.143	
Dyspnoea								
No	48	77.4%	14	22.6%				
Yes	148	53.2%	130	46.8%	12.14	1	0.001	**
Cough								
No	52	63.4%	30	36.6%				
Yes	142	55.9%	112	44.1%	1.43	1	0.249	
Haemoptysis								
No	169	59.5%	115	40.5%				
Yes	24	50.0%	24	50.0%	1.53	1	0.268	
Dyspnoea								
Lower	119	72.6%	45	27.4%				
Higher	77	43.8%	99	56.3%	28.86	1	<0.001	***
Cough								
Lower	136	63.6%	78	36.4%				
Higher	58	47.5%	64	52.5%	8.16	1	0.006	**
Haemoptysis								
Lower	183	58.7%	129	41.3%				
Higher	10	50.0%	10	50.0%	0.58	1	0.488	
Other symptoms								
Lower	180	66.7%	90	33.3%				
Higher	12	20.0%	48	80.0%	43.94	1	<0.001	***
Personal anxiety								
Lower	113	65.7%	59	34.3%				
Higher	80	50.0%	80	50.0%	8.39	1	0.004	**
Support network anxiety								
Lower	90	69.8%	39	30.2%				
Higher	102	50.7%	99	49.3%	11.68	1	0.001	**
Less ability to share								
Lower	157	61.3%	99	38.7%				
Higher	34	45.9%	40	54.1%	5.57	1	0.023	*
Reduced life-worth								
Lower	167	60.7%	108	39.3%				
Higher	18	41.9%	25	58.1%	5.44	1	0.030	*
Reduced self-esteem								
Lower	144	65.8%	75	34.2%				
Higher	44	42.3%	60	57.7%	15.93	1	<0.001	***
Information needs								
Lower	142	62.8%	84	37.2%				
Higher	35	42.7%	47	57.3%	9.99	1	0.002	**
Practical needs								
Lower	149	61.6%	93	38.4%				
Higher	33	46.5%	38	53.5%	5.14	1	0.028	*
Time wasted								
Lower	181	59.0%	126	41.0%				
Higher	3	25.0%	9	75.0%	5.46	1	0.033	*

Table 76: All patients attending the lung cancer clinic. Univariate analysis of factors across groups of higher and lower pain. Percentages adjusted for missing data. *p<0.05, **p<0.01 and ***p<0.001

Significant factors were entered into a backwards logistic regression model to test for independent effects. The following factors were added to the model: age, patient-rated PS, dyspnoea, cough, 'other' symptoms, personal anxiety, support network anxiety, ability to share, self-esteem, life-worth, information needs, practical needs and time wasted. In addition to these significant variables, additional factors of interest were included in the model: gender, presence of metastases and deprivation. Results are shown in Table 77.

						95% CI for Odds Ratios		
	b	SE	Wald	df	p value	Odds Ratio	Lower	Upper
Age >65	-.948	.311	9.302	1	.002	.388	.211	.713
Performance status 0-1			10.471	2	.005			
Performance status 2	.468	.375	1.563	1	.211	1.597	.767	3.328
Performance Status 3-4	1.119	.346	10.470	1	.001	3.061	1.554	6.028
Dyspnoea (higher)	1.011	.286	12.478	1	.000	2.748	1.568	4.815
Other symptoms (higher)	1.670	.396	17.761	1	.000	5.313	2.443	11.552
Constant	-.951	.289	10.808	1	.001	.386		

R^2=0.231 (Cox and Snell); 0.311 (Nagelkerke) Model X^2=73.74, df=5, p<0.001
Hosmer-Lemeshow test: X^2=3.069, df=6, p=0.800

Table 77: Independent factors associated with higher pain identified through backwards logistic regression for all patients.

A test of the full model against constant only model was statistically significant (model X^2=73.74, df=5, p<0.001). Nagelkerke's R^2 of 0.311 indicated that around 31% of variance was explained by the model. Overall prediction success was 73.0% (78.0% for lower pain and 65.8% for higher pain). The null model overall prediction of success was 58.4%. Each of the predictors in the final model was significant at the p<0.05 level. As such, higher levels of pain were independently associated with worse performance status, younger age, increased dyspnoea and increased 'other' symptoms. There were no significant effects from the other variables which were excluded from the final model. For a fixed age, level of dyspnoea and 'other' symptoms, a patient with a PS of 3-4 was 3.06 (95% CI 1.55-6.03) times more likely to have increased pain levels.

10.2.2 Pain in Newly Diagnosed Patients

Pain felt (mean 1.33, SD 1.33, median 1, range 0-4) was reported to be 'low' (0-1) in 54.7% (n=93/170) of newly diagnosed patients and high (2-4) in 42.9% (n=73/170). The factors tabulated below were evaluated for significant differences across lower and higher pain (Table 78).

	Lower Pain		Higher Pain					
Factor	Number	Percentage	Number	Percentage	χ^2	Df	p value	Significant
Gender								
Male	47	57.3%	35	42.7%				
Female	46	54.8%	38	45.2%	0.11	1	0.757	
Age								
<65 years	20	43.5%	26	56.5%				
≥65 years	73	60.8%	47	39.2%	4.065	1	0.055	
Histology								
Clinical	17	43.6%	22	56.4%				
NSCLC	60	58.3%	43	41.7%				
SCLC	16	66.7%	8	33.3%	3.758	2	0.153	
Stage NSCLC								
1A	16	69.6%	7	30.4%				
1B	29	60.4%	19	39.6%				
2A	8	38.1%	13	61.9%				
2B	14	70.0%	6	30.0%				
3A	16	59.3%	11	40.7%				
3B	35	49.3%	36	50.7%				
4	45	54.9%	37	45.1%	7.864	6	0.248	
Stage SCLC								
Limited	7	77.8%	2	22.2%				
Extensive	9	60.0%	6	40.0%	0.8	1	0.371	
Presence or absence of metastases								
None	57	57.0%	43	43.0%				
Metasases	36	54.5%	30	45.5%	0.97	1	0.873	
Time from diagnosis to POS								
Within 3 weeks	64	56.1%	50	43.9%				
3-6 weeks	29	55.8%	23	44.2%				
6 weeks to 3 months	0	.0%	0	.0%				
3-6 months	0	.0%	0	.0%				
6-12 months	0	.0%	0	.0%				
> 12 months	0	.0%	0	.0%	na			
Performance status rated by patients								
0-1	67	74.4%	23	25.6%				
2	13	40.6%	19	59.4%				
3-4	13	29.5%	31	70.5%	27.997	2	<0.001	***
Diagnosis PS, assessed by doctor								
0-1	60	67.4%	29	32.6%				
2	19	41.3%	27	58.7%				
3-4	4	57.1%	3	42.9%	8.519	2	0.014	*
Active anti-cancer treatment								
Yes	69	57.5%	51	42.5%				
No	14	56.0%	11	44.0%	0.19	1	1	
Deprivation								
Dep Cat 1-5	50	60.2%	33	39.8%				
Dep cat 6 or 7	43	53.1%	38	46.9%	0.855	1	0.431	
Satisfaction score								
0-4	44	55.7%	35	44.3%				
5-8	0	.0%	2	100.0%				
9-12	0	.0%	0	.0%	na			
GP attendance between clinics								
No	28	56.0%	22	44.0%				
Yes	23	52.3%	21	47.7%	0.131	1	0.836	
Dyspnoea								
No	23	76.7%	7	23.3%				
Yes	70	51.5%	66	48.5%	6.33	1	0.014	*
Cough								
No	22	59.5%	15	40.5%				
Yes	70	55.6%	56	44.4%	0.18	1	0.710	
Haemoptysis								
No	79	60.3%	52	39.7%				
Yes	14	46.7%	16	53.3%	1.86	1	0.219	
Dyspnoea								
Lower	57	69.5%	25	30.5%				
Higher	36	42.9%	48	57.1%	11.97	1	0.001	**
Cough								
Lower	63	61.2%	40	38.8%				
Higher	29	48.3%	31	51.7%	3.54	1	0.141	
Haemoptysis								
Lower	86	58.9%	60	41.1%				
Higher	7	46.7%	8	53.3%	0.84	1	0.417	
Other symptoms								
Lower	89	67.4%	43	32.6%				
Higher	4	13.8%	25	86.2%	28.01	1	<0.001	***
Personal anxiety								
Lower	49	69.0%	22	31.0%				
Higher	44	48.4%	47	51.6%	6.96	1	0.010	*
Support network anxiety								
Lower	30	78.9%	8	21.1%				
Higher	62	50.4%	61	49.6%	9.66	1	0.002	**
Less ability to share								
Lower	75	60.5%	49	39.5%				
Higher	16	43.2%	21	56.8%	3.45	1	0.088	
Reduced life-worth								
Lower	77	57.9%	56	42.1%				
Higher	10	45.5%	12	54.5%	1.19	1	0.355	
Reduced self-esteem								
Lower	68	63.6%	39	36.4%				
Higher	21	41.2%	30	58.8%	7.03	1	0.010	*
Information needs								
Lower	72	62.1%	44	37.9%				
Higher	14	36.8%	24	63.2%	7.39	1	0.008	**
Practical needs								
Lower	65	59.1%	45	40.9%				
Higher	22	48.9%	23	51.1%	1.35	1	0.286	
Time wasted								
Lower	84	56.4%	65	43.6%				
Higher	1	16.7%	5	83.3%	3.67	1	0.091	

Table 78: Newly diagnosed patients. Univariate analysis of factors across groups of higher and lower pain. Percentages are adjusted for missing data. *p<0.05, **p<0.01 and ***p<0.001

The factors identified as significant were: dyspnoea, 'other' symptoms, personal anxiety, support network anxiety, self-esteem and information needs. Significant factors were entered into a backwards logistic regression model to test for independent effects. In addition to these significant variables, additional factors of interest were included in the model: patient-rated PS, presence of metastases, age, gender and deprivation. Results are shown in Table 79.

						95% CI for Odds Ratios		
	b	SE	Wald	df	p value	Odds Ratio	Lower	Upper
Age >65	-1.350	.477	8.029	1	.005	.259	.102	.660
Performance status 0-1			18.564	2	.000			
Performance status 2	1.658	.566	8.587	1	.003	5.251	1.732	15.923
Performance Status 3-4	2.183	.539	16.406	1	.000	8.875	3.086	25.527
Other symptoms (higher)	2.087	.638	10.707	1	.001	8.058	2.309	28.122
Information needs (higher)	1.102	.498	4.892	1	.027	3.011	1.134	7.998
Constant	-.969	.418	5.366	1	.021	.380		

R^2=0.340 (Cox and Snell); 0.457 (Nagelkerke) Model X^2=60.64, df=5, p<0.001
Hosmer-Lemeshow test: X^2=3.311, df=6, p=0.769

Table 79: Independent factors associated with higher pain identified through backwards logistic regression for newly diagnosed patients.

A test of the full model against constant only model was statistically significant (model X^2=60.64, df=5, p<0.001). Nagelkerke's R^2 of 0.457 indicated that around 46% of variance was explained by the model. Overall prediction success was 78.1% (88.2% for lower pain and 63.9% for higher pain). This compares to the null model overall prediction success of 58.2%. Each of the predictors in the final model was significant at the p<0.05 level. As such, higher levels of pain were independently associated with younger age, worse performance status, higher 'other' symptoms and increased information needs. There were no significant effects from the other variables which were excluded from the final model. For a fixed age, level of information needs and 'other' symptoms, a patient with a PS of 3-4 was 8.875(95% CI 3.09-25.53) times more likely to have higher pain.

10.2.3 Pain in Patients in the Last Three Months of Life

Pain felt (mean 1.68, SD 1.33, median 2, range 0-4) was reported to be 'low' (0-1) in 39.7% (n=48/121) of patients within the last three months of life and high (2-4) in 57.1% (n=69/121). The factors tabulated below were evaluated for significant differences across lower and higher pain (Table 80).

	Lower Pain		Higher Pain					
Factor	Number	Percentage	Number	Percentage	χ^2	Df	p value	Significant
Gender								
Male	26	41.3%	37	58.7%				
Female	22	40.7%	32	59.3%	0.03	1	1	
Age								
<65 years	9	31.0%	20	69.0%				
≥65 years	39	44.3%	49	55.7%	1.591	1	0.277	
Histology								
Clinical	7	41.2%	10	58.8%				
NSCLC	29	36.7%	50	63.3%				
SCLC	12	57.1%	9	42.9%	2.863	2	0.239	
Stage NSCLC								
1A	1	100.0%	0	.0%				
1B	4	57.1%	3	42.9%				
2A	0	.0%	6	100.0%				
2B	0	.0%	3	100.0%				
3A	2	33.3%	4	66.7%				
3B	11	35.5%	20	64.5%				
4	17	40.5%	25	59.5%	7.915	6	0.244	
Stage SCLC								
Limited	3	50.0%	3	50.0%				
Extensive	9	60.0%	6	40.0%	0.175	1	0.676	
Presence or absence of metastases								
None	22	36.7%	38	63.3%				
Metasases	26	45.6%	31	54.4%	0.967	1	0.352	
Time from diagnosis to POS								
Within 3 weeks	11	36.7%	19	63.3%				
3-6 weeks	4	66.7%	2	33.3%				
6 weeks to 3 months	10	55.6%	8	44.4%				
3-6 months	9	50.0%	9	50.0%				
6-12 months	9	34.6%	17	65.4%				
> 12 months	5	26.3%	14	73.7%	6.177	5	0.289	
Performance status rated by patients								
0-1	19	52.8%	17	47.2%				
2	12	41.4%	17	58.6%				
3-4	17	32.7%	35	67.3%	3.549	2	0.17	
Diagnosis PS, assessed by doctor								
0-1	27	43.5%	35	56.5%				
2	16	42.1%	22	57.9%				
3-4	3	42.9%	4	57.1%	0.2	2	0.99	
Active anti-cancer treatment								
Yes	33	38.8%	52	61.2%				
No	11	55.0%	9	45.0%	1.74	1	0.214	
Deprivation								
Dep Cat 1-5	24	39.3%	37	60.7%				
Dep cat 6 or 7	24	42.9%	32	57.1%	0.149	1	0.711	
Albumin at diagnosis								
<35	24	46.2%	28	53.8%				
≥35	23	37.1%	39	62.9%	0.957	1	0.346	
CRP at diagnosis								
<10	18	43.9%	23	56.1%				
≥10	30	39.5%	46	60.5%	0.216	1	0.696	
Glasgow Prognostic Score								
CRP <10 and Albumin >35	13	48.1%	14	51.9%				
CRP >10 or Albumin <35	12	27.3%	32	72.7%				
CRP >10 and Albumin <35	21	50.0%	21	50.0%	5.412	2	0.067	
Satisfaction score								
0-4	20	36.4%	35	63.6%				
5-8	0	.0%	1	100.0%				
9-12	0	.0%	0	.0%	na			
GP attendance between clinics								
No	11	50.0%	11	50.0%				
Yes	12	30.0%	28	70.0%	2.433	1	0.17	
Dyspnoea								
No	12	63.2%	7	36.8%				
Yes	36	36.7%	62	63.3%	4.59	1	0.042	*
Cough								
No	15	45.5%	18	54.5%				
Yes	32	39.0%	50	61.0%	0.40	1	0.537	
Haemoptysis								
No	44	46.8%	50	53.2%				
Yes	3	15.8%	16	84.2%	6.26	1	0.020	*
Dyspnoea								
Lower	26	61.9%	16	38.1%				
Higher	22	29.3%	53	70.7%	11.81	1	0.001	**
Cough								
Lower	29	45.3%	35	54.7%				
Higher	18	35.3%	33	64.7%	1.18	1	0.341	
Haemoptysis								
Lower	45	42.5%	61	57.5%				
Higher	2	28.6%	5	71.4%	0.52	1	0.697	
Other symptoms								
Lower	40	54.1%	34	45.9%				
Higher	7	17.9%	32	82.1%	13.71	1	<0.001	***
Personal anxiety								
Lower	26	52.0%	24	48.0%				
Higher	21	33.3%	42	66.7%	4.00	1	0.056	
Support network anxiety								
Lower	18	58.1%	13	41.9%				
Higher	30	36.1%	53	63.9%	4.45	1	0.054	
Less ability to share								
Lower	36	43.4%	47	56.6%				
Higher	11	34.4%	21	65.6%	0.77	1	0.406	
Reduced life-worth								
Lower	40	43.5%	52	56.5%				
Higher	7	31.8%	15	68.2%	1.00	1	0.347	
Reduced self-esteem								
Lower	32	46.4%	37	53.6%				
Higher	15	32.6%	31	67.4%	2.17	1	0.176	
Information needs								
Lower	34	41.0%	49	59.0%				
Higher	12	38.7%	19	61.3%	0.05	1	1.000	
Practical needs								
Lower	31	37.8%	51	62.2%				
Higher	16	50.0%	16	50.0%	1.41	1	0.291	
Time wasted								
Lower	47	42.3%	64	57.7%				
Higher	0	.0%	4	100.0%	2.86	1	0.144	

Table 80: Patients who died within three months of questionnaire completion. Univariate analysis of factors across groups of higher and lower pain. Percentages are adjusted for missing data. *p<0.05, **p<0.01 and ***p<0.001

The factors identified as significant were: dyspnoea, haemoptysis and 'other' symptoms. These factors were entered into a backwards logistic regression model to test for independent effects. In addition to these significant variables, additional factors of interest were included in the model: gender, age, patient-rated PS, presence of metastases and deprivation. Results are shown in (Table 81).

						95% CI for Odds Ratios		
	b	SE	Wald	df	p value	Odds Ratio	Lower	Upper
Dyspnoea (higher)	1.092	.435	6.294	1	.012	2.981	1.270	6.997
Other symptoms (higher)	1.463	.492	8.829	1	.003	4.320	1.646	11.340
Constant	-.783	.351	4.971	1	.026	.457		

R^2=0.170 (Cox and Snell); 0.229 (Nagelkerke) Model X^2=21.06, df=2, p<0.001
Hosmer-Lemeshow test: X^2=0.141, df=2, p=0.932

Table 81: Independent factors associated with higher pain identified through backwards logistic regression for patients in the last three months of life.

A test of the full model against constant only model was statistically significant (model X^2=21.06, df=2, p<0.001). Nagelkerke's R^2 of 0.229 indicated that around 23% of variance was explained by the model. Overall prediction success was 69.9% (48.9% for lower pain and 84.8% for higher pain). This compares to the null model overall prediction success of 58.4%. Each of the predictors in the final model was significant at the p<0.05 level. As such, higher levels of pain were independently associated with increased dyspnoea and increased 'other' symptoms. There were no significant effects from the other variables which were excluded from the final model. For a fixed level of 'other' symptoms, a patient with increased dyspnoea was 2.981 (95% CI 1.27-6.99) times more likely to have higher pain.

10.3 Discussion

The current study confirms the high prevalence of pain in the Stobhill lung cancer population. Furthermore, pain was rated as moderate, severe or overwhelming by four out of ten patients attending the lung cancer clinic (Section 6.2.1.1). Pain in lung cancer is well recognised to cause patients distress and be one their main concerns.[401] Despite this, pain remains undertreated in the lung cancer population.[404] Pain can result from the cancer itself, treatment-related effects or from co-morbidity. In lung cancer, pain can be present from early stage[404] until later stage.[399] Irrespective of its origin, pain can usually be managed once identified.[400]

In lung cancer, increased pain has been reported to be associated with a variety of factors including: histological subtype, stage of disease, gender, younger age and

treatment received. However, these reports are variable and inconsistent with underlying differences in methodology, sample characteristics and assessment tools.[401] Potter and Higginson[401] undertook a systematic review of such studies and reported on pain profiles in lung cancer. In this review, they reported the prevalence of pain as 27% (range 8-85%) in outpatients, 36% (range 9-58%) in general hospital in-patients, 76% (range 63-88%) in patients referred to palliative care and 100% in patients referred to pain teams with an overall prevalence of 47% (6-100%) in the lung cancer population.[401]

In the current study, pain was a highly rated physical symptom: 40.1% of patients overall, 42.9% of newly diagnosed patients and 57.1% of patients in the last three months of life described moderate to overwhelming pain. The potential predictors of increased pain (moderate-overwhelming) were explored utilising univariate and multivariate analyses. The main factors identified associated with increased pain were: younger age, worse PS, physical symptoms of dyspnoea and 'other'symptoms. Information needs were also found to be significant in newly diagnosed patients. Factors that were not related to the level of pain on univariate analyses included gender, histology, stage, active treatment and deprivation level.

10.3.1 Performance Status

PS is a global assessment of function.[405] In the current study, worse PS rated by the patient was strongly related to increased pain levels. In multivariate analysis, this study revealed PS was an independent predictor of increased pain in the whole clinic population and in newly diagnosed patients. Performance status was not an independent factor in the last three months of life. It may be that within the current study population there were insufficient numbers to detect a difference between PS groups, especially given the finding that poorer PS is strongly correlated with reduced survival.

In their multivariate study, Lin et al[406] reported significantly lower PS (measured by Karnofsky PS) in Taiwanese lung cancer patients experiencing pain. Pain intensity and pain interference with life were both significantly correlated with worse performance status. This is in keeping with the higher pain prevalence reported in patients with PS 2 compared to PS 0-1 in Italian patients with NSCLC.[407] Ferreira et al[323] identified that a number of symptoms may relate to reduced functional status in cancer. They further elucidated the most important predictor of reduced PS was fatigue but pain was the next

most important predictor. The two symptoms together explained 38% of variance in the model predicting reduced functional status. Gift et al[285] also reported reduced functioning relating to six main symptoms including pain and fatigue in lung cancer patients.

Vallerand et al[408] explored the relationship between pain occurrence, pain-related distress, functioning and perceived control over pain. They reported that a patient's pain level is related to increased distress and reduced control over pain and functional status. Through further modelling, they reported that symptom distress mediated this relationship. This in keeping with 'The Theory of Unpleasant Symptoms'[409] discussed and assessed by Gift et al[298] in a lung cancer population. This theoretical framework considered the relationship between symptom occurrence, distress, timing and quality alongside additional symptoms, performance, psycho-emotional environment and contextual factors (such as cancer recurrence, entering the terminal phase or previous experience of such symptoms). In such a complex interplay of factors, pain and pain-related distress can relate to reduction in performance status leading to worsening psycho-emotional state and further increase in distress. Increased distress can, in turn, lead to an increase in perceived pain.[298, 409]

10.3.2 Age

In the current study, increased pain levels were independently associated with younger patients (<65 years) in the general clinic population and newly diagnosed patients. This finding has been previously reported.[401] Maio et al[407] reported increased moderate-severe pain in younger patients with NSCLC than older patients. De Maria et al[287] described significantly increased pain in lung cancer patients less than 70 years old. Kuo et al[410] also reported an increased level of pain at diagnosis in younger patients (40 years and younger) compared to elderly patients (>80years) with lung cancer.

10.3.3 Physical Symptoms

Lung cancer patients often experience multiple symptoms (see Section 1.5) However, in the current study, increased pain was associated with the physical symptoms of increased dyspnoea and 'other' symptoms. In the general lung cancer clinic population, other significant factors in the model included PS and age; in newly diagnosed patients, PS, age and information needs were included; in the last three months of life, however,

the only significant predictors of increased pain were increased dyspnoea and 'other' symptoms.

Pain has been associated with increased dyspnoea in seriously ill patients in a previous hospital based study.[411] In a large hospital based study (n=1556), Desbiens et al[411] controlled for depression, anxiety, disease type and severity, location of patient and QOL and reported that increased dyspnoea was an independent predictor of increased pain levels. Furthermore, in lung cancer patients, Tanaka et al[412] reported that pain was an independent predictor of increased breathlessness alongside cough, psychological distress and 'organic causes'. It is not clear what underlies this association between pain and dyspnoea. This may be a simple co-occurrence in lung cancer or there may be a direct link through altered sensitivity to pain in dyspnoeic patients.[411] It has recently been postulated that both pain and dyspnoea share common pathways within the nervous system and that the 'unpleasantness' associated with both these common symptoms is mediated through an aversive signalling pathway.[413-416]

In the current study, the other predictive factor for increased pain was 'other' symptoms. Unfortunately, despite the questionnaire allowing patients to detail what the 'other' symptoms were, very few reported what was that was troubling them. In previous cancer symptom studies, pain has been associated with the presence of constipation.[417] It has been postulated that this relationship may be mediated through the prescription of constipating analgesics such as opioids.[417] Other symptoms associated with pain in the cancer population include fatigue[418] and nausea.[411] It is not clear in this study what the 'other' symptoms associated with pain are, but it is relevant to note that the presence of pain in a lung cancer patient should prompt further assessment for the presence of dyspnoea and other symptoms. This is in keeping with the finding of multiple studies that lung cancer patients experience multiple symptoms throughout their cancer journey (see Section 5).

10.3.4 Information Needs

Hsu et al[419] reported on the relationship between pain, uncertainty and hope in Taiwanese patients with lung cancer. Pain severity itself was associated with uncertainty in either univariate or multivariate analysis. A relationship was identified between uncertainty and the level of interference with normal life that pain was causing. In this study, the Mishel uncertainty illness scale was used to evaluate the individual's

perception of uncertainty regarding symptoms, diagnosis, treatment, prognosis and personal relationships. In the current study, increased unmet information needs were independently associated with increased pain in newly diagnosed patients. This may relate to the relationship between uncertainty and pain described by Hsu et al.[419] It is also possible that the presence of pain itself creates uncertainty or the desire for increased information. In newly diagnosed patients with increased pain, there may, therefore, be increased information needs which should be elicited and addressed.

10.3.5 Non-Significant Factors

In the current study, multivariate analysis found no significant relationships between increased pain and gender, histology, stage of disease, deprivation level, albumin, CRP, time from diagnosis, active anti-cancer treatments, cough, haemoptysis, anxiety, ability to share, self-esteem, life-worth, practical needs and time use.

Previous studies have also reported that gender has no influence on pain levels in lung cancer.[216, 300, 407, 418, 420] Huhti et al[421] reported no difference in short term symptoms (less than six months in duration) between men and women with lung cancer, with the exception of increased sputum production in females. They did find increased long term pain in females. Overall, the literature is consistent with the finding that gender does not appear to influence pain in lung cancer.

The current study found no difference in pain experience between histological subtypes of lung cancer. There has been conflicting evidence reported regarding this previously. One study reported increased pain levels at presentation in patients with NSCLC compared to SCLC;[292] another study reported the opposite finding with increased pain in SCLC.[421] Consistent with the current study, Chute et al[422] report no difference in pain between histological subtypes.

Increased pain has been previously described in relation to increased stage of lung cancer.[401] The situation is complicated through studies considering patients in different settings and at different points of their cancer journey. In their systematic review, Potter et al[401] reported that weighted mean prevalence of pain at presentation was 41% (range 30-71%). Pain prevalence in the palliative setting was higher. However, in keeping with the 100% prevalence of pain in patients referred to pain services in this review, there is

likely to be some bias towards active symptoms in patients referred to palliative care services.

The current study also found no relationship between time from diagnosis and pain. Chute et al[422] reported that chest pain did not predict stage but the presence of extra-thoracic pain was predictive of stage 3 disease. Maio et al[407] described significantly increased pain on univariate analysis in patients with stage 4 NSCLC compared to patients with stage 3 NSCLC. Further research is needed to elucidate the relationship between pain and stage of disease, taking into account confounding variables. In keeping with the current study, many of the previous studies were not able to provide data on analgesic use or response to their analgesics. It remains unclear whether pain is a good clinical marker of advanced disease, disease progression or if increasing analgesic load may also act as a surrogate for evidence of advanced disease.

No previous studies have reported on the relationship between pain and deprivation in lung cancer patients. In the current study, there was no significant relationship found between level of deprivation and pain reported in any of the clinical groups studied. No previous studies have evaluated the relationship between albumin level or CRP level and pain in lung cancer patients. There was no significant relationship found in this study.

Treatment type has been previously described as influencing pain experienced. Post-thoracotomy pain is well described in lung cancer patients,[269] and both chemotherapy[423] and radiotherapy[400] can cause painful neuropathy. However, each of these modalities can also provide improved symptom control including control of pain.[97] Furthermore, patients receiving active treatments are under active surveillance for toxicities and treatment response. Such increased monitoring may also have a beneficial effect on overall symptom control. Potter et al[401] reported that most pain in lung cancer is multi-factorial but the majority does relate to the disease itself. In their review, the weighted mean prevalence of pain attributable to anti-cancer treatments (irrespective of type) was 13% (range 5-17%). Despite this, they note that there is little evidence that prevalence of pain is related to treatment modality.[401]

Previous studies in the non-cancer setting have described a relationship between pain and psychological variables such as depression[424-427] and anxiety.[424, 428-430] In cancer, a

similar relationship between increased pain and increased anxiety[178, 370, 381, 431-433] or increased depression[376, 380, 431, 432, 434, 435] has been described. Furthermore, functional MRI scanning studies have suggested specific demonstrable links between pain and depression[436] and pain and anxiety.[437]

In their multivariate analysis of pain, depression and cancer type, Fischer et al[432] described increased pain levels and distress in lung cancer patients compared to those with head and neck cancers or prostate cancer. They also found that increased anxiety, increased depression and having lung cancer were all independent predictors of higher pain levels. However, research in this area is difficult due to probable relationships between anxiety and depression themselves,[386, 424, 438] multiple assessment tools,[439] confounding variables and crossover features in the assessment of anxiety, pain and depression.[435, 440] In Section 9 in the current study, the strong relationship between low self-esteem and anxiety in lung cancer has already been described. Section 9 also makes clear that anxiety is a key supportive care need in lung cancer patients. However, its relationship to pain remains unclear.

In the current study, for all patients attending the clinic and for newly diagnosed patients, strong bivariate relationships were found between increased pain and both increased personal anxiety and increased perceived anxiety in the support network. Neither of these relationships was found in the last three months of life. This may reflect the lack of numbers within the three month grouping or that this relationship was modified by the use of symptom control measures targeted within the last three months of life. On multivariate analysis, anxiety (either personal or support network) was not a significant independent predictor of increased pain in any of the clinical groupings. Previous studies in lung cancer have also described high levels of anxiety at different stages of the illness.[2] There are few published studies examining the relationship between pain and anxiety specifically in lung cancer. The study of Fischer et al[432] in a variety of cancer types further examined interdependent relationships within the lung cancer population. Although other studies in the cancer setting do describe a relationship, many are univariate analyses and may not be directly applicable to lung cancer patients. However, from the emerging physiological evidence of linkage between anxiety and increased pain,[437] the background of non-cancer studies, the evidence of some cancer studies and the high prevalence of both pain and anxiety in lung cancer, this is clearly an area which merits further research.

There is also a high prevalence of depression in the lung cancer population.[2, 342] Laird et al[435] carried out a systematic review of evidence for an interdependent relationship between cancer pain and depression in 2009. Fourteen studies were identified which contained information indentifying a relationship between pain and depression. However, none of these studies identified were specifically designed to examine this relationship. Prevalence of depression ranged from 22.1% to 46% but this was complicated through the use of multiple different assessment methods. A positive statistical relationship was identified between increased pain and increased depression in nine studies, of which only one utilised multivariate analysis. The authors concluded that, although there is some evidence of an association between depression and increased cancer related pain, there is insufficient evidence to conclude a causal relationship.

In lung cancer, there are no studies looking specifically at the relationship between pain and depression. Hopwood et al[380] reported on depression and risk factors derived from quality of life data obtained in trials involving lung cancer patients. They reported a strong independent relationship between reduced performance status and increased depression. They also described increased levels of depression independently associated with higher overall symptom burden. Further detailed evaluation of the data showed that increased depression was associated with certain symptoms at presentation, including general pain, chest pain, fatigue, dyspnoea and cough.

In the current study, increased pain was associated with reduced self-esteem ($p<0.001$) and reduced life-worth ($p=0.03$) in the general clinic population. This relationship between reduced self-esteem and increased pain was also observed in newly diagnosed patients ($p=0.01$), but there was no significant relationship between pain and self-worth. Neither of these psychosocial variables was significantly associated with increased pain in the last three months of life. Again, this may relate to under-powering for this group. On multivariate analysis, neither reduced self-worth nor reduced life-worth were independent predictors of increased pain. Again, given the lack of current evidence but the high prevalence of both pain and depression in lung cancer, and the emerging physiological evidence of a possible link between the two factors,[436] further research into this area is necessary to elucidate the relationship between pain and depression in the lung cancer setting.

10.4 Conclusions

Pain is an important issue in lung cancer care. Lung cancer patients experience high levels of pain and associated distress. Pain can be managed, once identified, in the majority of patients with cancer. In lung cancer, a significant proportion of patients may have complex pain requiring particular attention and individually tailored approaches to analgesia. The current study confirms the significant prevalence of pain within the Stobhill lung cancer out-patient population.

On multivariate analyses, increased levels of pain were not predicted by gender, stage, histology, deprivation, active treatment, anxiety or depression. However, in the general clinic population, increased pain was independently related to poorer performance status, younger age, dyspnoea and 'other' symptoms. In newly diagnosed lung cancer patients, increased pain was related to the same variables and increased unmet information needs. In the last three months of life, increased pain was associated with dyspnoea and 'other' symptoms but no other variables in this study.

For lung cancer patients, pain is consistently rated as one of their highest concerns. Although a systematic approach to assessing symptoms should include pain assessment, the findings in the current study suggest it would be appropriate to focus attention on those with reduced performance status, younger patients and those with dyspnoea to identify any uncontrolled pain.

11 Dyspnoea in Lung Cancer

In keeping with Aim 4c, this section evaluates the predictors of increased dyspnoea in the Stobhill lung cancer clinic population. The predictors evaluated were all readily available within the Stobhill clinical service and may serve to allow effective and efficient targeting of dyspnoea management within the service. The methodology and statistical approach is outlined in Section 3.

11.1 Introduction

Dyspnoea has been defined as:

> *A subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity. The experience derives from interactions among multiple physiological, psychological, social, and environmental factors, and may induce secondary physiological and behavioural responses.*[441]

This broad definition has been designed to encompass a variety of sensations that can be reported as 'breathlessness' and to aid in the understanding of dyspnoea as a complex symptom that is influenced by physical, psychosocial and emotional factors.[442] Dyspnoea is a common symptom in lung cancer and is associated with high distress[442] (see Section 1.5). Furthermore, chronic obstructive airways disease is a common co-morbidity in lung cancer patients,[190, 228] and this is also associated with a high prevalence of distressing breathlessness.[178] In the current study, dyspnoea was rated as the most troubling physical symptom. A further evaluation of dyspnoea in lung cancer has been completed.

11.1.1 Dyspnoea in All Patients Attending the Lung Cancer Clinic

Dyspnoea felt (mean 1.55, SD 1.06, median 2, range 0-4) was reported to be low (0-1) in 47% (n=166/353) of all patients and high (2-4) in 49.8% (n=176/353). The factors tabulated below were evaluated for significant differences across lower and higher dyspnoea (Table 82).

	Lower Dyspnoea		Higher Dyspnoea					
Factor	Number	Percentage	Number	Percentage	χ^2	Df	p value	Significant
Gender								
Male	84	50.3%	83	49.7%				
Female	82	46.9%	93	53.1%	0.405	1	0.589	
Age								
<65 years	45	46.4%	52	53.6%				
≥65 years	121	49.4%	124	50.6%	0.25	1	0.633	
Histology								
Clinical	30	46.9%	34	53.1%				
NSCLC	115	48.7%	121	51.3%				
SCLC	21	50.0%	21	50.0%	0.11	2	0.946	
Stage NSCLC								
1A	9	37.5%	15	62.5%				
1B	28	58.3%	20	41.7%				
2A	11	52.4%	10	47.6%				
2B	12	60.0%	8	40.0%				
3A	11	40.7%	16	59.3%				
3B	33	46.5%	38	53.5%				
4	28	45.8%	45	54.2%	5.215	6	0.517	
Stage SCLC								
Limited	8	53.3%	7	46.7%				
Extensive	13	50.0%	13	50.0%	0.042	1	0.837	
Presence or absence of metastases								
None	115	49.4%	118	50.6%				
Metasases	51	46.8%	58	53.2%	0.196	1	0.728	
Time from diagnosis to POS								
Within 3 weeks	55	48.2%	59	51.8%				
3-6 weeks	27	51.9%	25	48.1%				
6 weeks to 3 months	17	53.1%	15	46.9%				
3-6 months	15	36.6%	26	63.4%				
6-12 months	21	53.8%	18	46.2%				
> 12 months	28	45.9%	33	54.1%	3.441	5	0.632	
Performance status rated by patients								
0-1	114	63.0%	67	37.0%				
2	19	27.9%	49	72.1%				
3-4	33	35.5%	60	64.5%	33.014	2	<0.001	***
Diagnosis PS, assessed by doctor								
0-1	111	52.1%	102	47.9%				
2	32	40.5%	47	59.5%				
3-4	5	55.6%	4	44.4%	3.257	2	0.196	
Active anti-cancer treatment								
Yes	130	48.7%	137	51.3%				
No	22	47.8%	24	52.2%	0.914	1	1	
Deprivation								
Dep Cat 1-5	79	50.6%	77	49.4%				
Dep cat 6 or 7	85	47.2%	95	52.8%	0.391	1	0.585	
Satisfaction score								
0-4	72	56.3%	56	43.8%				
5-8	2	66.7%	1	33.3%				
9-12	0	.0%	0	.0%	na			
GP attendance between clinics								
No	47	61.8%	29	38.2%				
Yes	36	48.0%	39	52.0%	2.922	1	0.103	
Cough								
No	55	66.3%	28	33.7%				
Yes	108	42.5%	146	57.5%	14.12	1	<0.001	***
Haemoptysis								
No	140	49.0%	146	51.0%				
Yes	21	43.8%	27	56.3%	0.45	1	0.536	
Cough								
Lower	128	59.3%	88	40.7%				
Higher	35	28.9%	86	71.1%	28.58	1	<0.001	***
Haemoptysis								
Lower	150	47.8%	164	52.2%				
Higher	11	55.0%	9	45.0%	0.39	1	0.646	
Pain								
Lower	119	60.7%	77	39.3%				
Higher	45	31.3%	99	68.8%	28.86	1	<0.001	***
Other symptoms								
Lower	146	53.7%	126	46.3%				
Higher	15	25.0%	45	75.0%	16.18	1	<0.001	***
Personal anxiety								
Lower	101	58.4%	72	41.6%				
Higher	61	37.9%	100	62.1%	14.02	1	<0.001	***
Support network anxiety								
Lower	77	58.8%	54	41.2%				
Higher	83	41.3%	118	58.7%	9.71	1	0.002	**
Less ability to share								
Lower	130	50.8%	126	49.2%				
Higher	31	41.3%	44	58.7%	2.07	1	0.189	
Reduced life-worth								
Lower	142	51.3%	135	48.7%				
Higher	13	30.2%	30	69.8%	6.59	1	0.013	*
Reduced self-esteem								
Lower	132	60.0%	88	40.0%				
Higher	26	25.0%	78	75.0%	34.62	1	<0.001	***
Information needs								
Lower	120	53.1%	106	46.9%				
Higher	30	36.6%	52	63.4%	6.57	1	0.014	**
Practical needs								
Lower	123	50.6%	120	49.4%				
Higher	33	46.5%	38	53.5%	0.38	1	0.590	
Time wasted								
Lower	155	50.3%	153	49.7%				
Higher	1	8.3%	11	91.7%	8.15	1	0.006	**

Table 82: All patients attending the lung cancer clinic. Univariate analysis of factors across groups of higher and lower dyspnoea. Percentages adjusted for missing data. *p<0.05, **p<0.01 and ***p<0.001

Significant factors were entered into a backwards logistic regression model to test for independent effects. Thus the following factors were added to the model: histology, cough, pain, 'other' symptoms, personal anxiety, support network anxiety, life-worth,

self-esteem, information needs and time wasted. Time wasted was not included in the final model due to the large confidence interval. In addition to these significant variables, additional factors of interest were included in the model: age, gender, presence of metastases, deprivation and patient-rated performance status. Results are shown in Table 83.

						95% CI for Odds Ratios		
	b	SE	Wald	df	p value	Odds Ratio	Lower	Upper
Performance status 0-1			7.645	2	.022			
Performance status 2	.973	.352	7.642	1	.006	2.645	1.327	5.273
Performance Status 3-4	.289	.357	.658	1	.417	1.335	.664	2.686
Cough (higher)	.731	.285	6.573	1	.010	2.078	1.188	3.634
Pain (higher)	1.007	.277	13.233	1	.000	2.739	1.591	4.713
Reduced self-esteem	.918	.322	8.124	1	.004	2.505	1.332	4.711
Constant	-1.149	.216	28.381	1	.000	.317		

R^2=0.194 (Cox and Snell); 0.258 (Nagelkerke) Model X^2=62.40, df=5, p<0.001
Hosmer-Lemeshow test: X^2=3.685, df=6, p=0.719

Table 83: Independent factors associated with higher dyspnoea identified through backwards logistic regression for all patients.

A test of the full model against constant only model was statistically significant (model X^2=62.40, df=5, p<0.001). Nagelkerke's R^2 of 0.258 indicated that around 26% of variance was explained by the model. Overall prediction success was 70.3% (71.9% for lower dyspnoea and 68.9% for higher dyspnoea). This compares to the null model overall prediction success of 52.1%. Each of the predictors in the final model was significant at the p<0.05 level. As such, higher dyspnoea levels were independently associated with reduced performance status, increased cough, increased pain and reduced self-esteem. There were no significant effects from the other variables which were excluded from the final model. For a fixed level of cough, pain and self-esteem, a patient with a PS of 3-4 was 1.34 (95% CI 0.664-3.634) times more likely to have higher dyspnoea.

11.1.2 Dyspnoea in Newly Diagnosed Patients

Dyspnoea felt (mean 1.56, SD 1.07, median 2, range 0-4) was reported to be low (0-1) in 48.2% (n=82/170) of newly diagnosed patients and high (2-4) in 49.4% (n=84/170). The factors tabulated below were evaluated for significant differences across lower and higher dyspnoea (Table 84).

	Lower Dyspnoea		Higher Dyspnoea					
Factor	Number	Percentage	Number	Percentage	χ^2	Df	p value	Significant
Gender								
Male	42	51.2%	40	48.8%				
Female	40	47.6%	44	52.4%	0.215	1	0.756	
Age								
<65 years	23	50.0%	23	50.0%				
≥65 years	59	49.2%	61	50.8%	0.009	1	1	
Histology								
Clinical	19	48.7%	20	51.3%				
NSCLC	51	49.5%	52	50.5%				
SCLC	12	50.0%	12	50.0%	0.011	2	0.994	
Stage NSCLC								
1A	2	66.7%	1	33.3%				
1B	12	70.6%	5	29.4%				
2A	7	63.6%	4	36.4%				
2B	2	40.0%	3	60.0%				
3A	8	47.1%	9	52.9%				
3B	13	38.2%	21	61.8%				
4	24	47.1%	27	52.9%	6.324	6	0.388	
Stage SCLC								
Limited	5	55.6%	4	44.4%				
Extensive	7	46.7%	8	53.3%	0.178	1	0.673	
Presence or absence of metastases								
None	51	51.0%	49	49.0%				
Metasases	31	47.0%	35	53.0%	0.258	1	0.637	
Time from diagnosis to POS								
Within 3 weeks	55	48.2%	59	51.8%				
3-6 weeks	27	51.9%	25	48.1%				
6 weeks to 3 months	0	.0%	0	.0%				
3-6 months	0	.0%	0	.0%				
6-12 months	0	.0%	0	.0%				
> 12 months	0	.0%	0	.0%	na			
Performance status rated by patients								
0-1	59	65.6%	31	34.4%				
2	8	25.0%	24	75.0%				
3-4	15	34.1%	29	65.9%	21.145	1	<0.001	***
Diagnosis PS, assessed by doctor								
0-1	50	56.2%	39	43.8%				
2	17	37.0%	29	63.0%				
3-4	4	57.1%	3	42.9%	4.633	2	0.099	
Active anti-cancer treatment								
Yes	60	50.0%	60	50.0%				
No	12	48.0%	13	52.0%	0.033	1	1	
Deprivation								
Dep Cat 1-5	42	50.6%	41	49.4%				
Dep cat 6 or 7	39	48.1%	42	51.9%	0.099	1	0.758	
Satisfaction score								
0-4	45	57.0%	34	43.0%				
5-8	1	50.0%	1	50.0%				
9-12	0	.0%	0	.0%	na			
GP attendance between clinics								
No	33	66.0%	17	34.0%				
Yes	19	43.2%	25	56.8%	4.93	1	0.037	*
Cough								
No	25	67.6%	12	32.4%				
Yes	55	43.7%	71	56.3%	6.55	1	0.015	*
Haemoptysis								
No	68	51.9%	63	48.1%				
Yes	11	36.7%	19	63.3%	2.27	1	0.158	
Cough								
Lower	63	61.2%	40	38.8%				
Higher	17	28.3%	43	71.7%	16.35	1	<0.001	***
Haemoptysis								
Lower	72	49.3%	74	50.7%				
Higher	7	46.7%	8	53.3%	0.04	1	1.000	
Pain								
Lower	57	61.3%	36	38.7%				
Higher	25	34.2%	48	65.8%	11.97	1	0.001	**
Other symptoms								
Lower	70	53.0%	62	47.0%				
Higher	9	31.0%	20	69.0%	4.60	1	0.040	*
Personal anxiety								
Lower	42	59.2%	29	40.8%				
Higher	37	40.7%	54	59.3%	5.46	1	0.026	*
Support network anxiety								
Lower	24	63.2%	14	36.8%				
Higher	54	43.9%	69	56.1%	4.31	1	0.043	*
Less ability to share								
Lower	65	52.4%	59	47.6%				
Higher	15	40.5%	22	59.5%	1.61	1	0.261	
Reduced life-worth								
Lower	69	51.9%	64	48.1%				
Higher	8	36.4%	14	63.6%	1.82	1	0.250	
Reduced self-esteem								
Lower	61	57.0%	46	43.0%				
Higher	18	35.3%	33	64.7%	6.52	1	0.017	*
Information needs								
Lower	59	50.9%	57	49.1%				
Higher	19	50.0%	19	50.0%	0.01	1	1.000	
Practical needs								
Lower	58	52.7%	52	47.3%				
Higher	20	44.4%	25	55.6%	0.88	1	0.380	
Time wasted								
Lower	75	50.3%	74	49.7%				
Higher	1	16.7%	5	83.3%	2.62	1	0.210	

Table 84: Newly diagnosed patients. Univariate analysis of factors across groups of higher and lower dyspnoea. Percentages are adjusted for missing data. *p<0.05, **p<0.01 and ***p<0.001

The factors identified as significant were: PS rated by patients during LCQ completion, GP attendance, cough, pain, 'other' symptoms, personal anxiety, support network anxiety and self-esteem. Significant factors were entered into a backwards logistic regression model to test for independent effects. Frequency of review was not entered as this was likely to be related to ongoing active issues rather than a useful predictor of increased dyspnoea. In addition to these significant variables, additional factors of interest were included in the model: age, gender, presence of metastases and deprivation. Results are shown in Table 85.

						95% CI for Odds Ratios		
	b	SE	Wald	df	p value	Odds Ratio	Lower	Upper
Cough (higher)	1.171	.376	9.723	1	.002	3.225	1.545	6.734
Pain (higher)	1.141	.360	10.027	1	.002	3.129	1.544	6.341
Constant	-.831	.258	10.401	1	.001	.436		

R^2=0.143 (Cox and Snell); 0.191 (Nagelkerke) Model X^2=23.33, df=3, p<0.001
Hosmer-Lemeshow test: X^2=1.930, df=2, p=0.381

Table 85: Independent factors associated with higher dyspnoea identified through backwards logistic regression for newly diagnosed patients.

A test of the full model against constant only model was statistically significant (model X^2=23.33, df=3, p<0.001). Nagelkerke's R^2 of 0.191 indicated that around 19% of variance was explained by the model. Overall prediction success was 69.5% (60.8% for lower dyspnoea and 77.9% for higher dyspnoea). This compares to the null model overall prediction success of 51%. Each of the predictors in the final model was significant at the p<0.05 level. As such, higher levels of dyspnoea were independently associated with increased cough and increased pain. There were no significant effects from the other variables which were excluded from the final model. For a fixed level of cough, a patient with higher pain was 3.129 (95% CI 1.54-6.34) times more likely to have increased dyspnoea.

11.1.3 Dyspnoea in Patients in the Last Three Months of Life

Dyspnoea felt (mean 1.92, SD 1.23, median 2, range 0-4) was reported to be low (0-1) in 34.7% (n=42/121) of patients within the last three months of life and high (2-4) in 61.9% (n=75/121). The factors tabulated below were evaluated for significant differences across lower and higher dyspnoea (Table 86).

	Lower Dyspnoea		Higher Dyspnoea					
Factor	Number	Percentage	Number	Percentage	χ^2	df	p value	Significant
Gender								
Male	23	36.5%	40	63.5%				
Female	19	35.2%	35	64.8%	0.022	1	1	
Age								
<65 years	11	37.9%	18	62.1%				
≥65 years	31	35.2%	57	64.8%	0.069	1	0.826	
Histology								
Clinical	9	52.9%	8	47.1%				
NSCLC	22	27.8%	57	72.2%				
SCLC	11	52.4%	10	47.6%	6.85	1	0.033	*
Stage NSCLC								
1A	0	.0%	1	100.0%				
1B	4	57.1%	3	42.9%				
2A	2	33.3%	4	66.7%				
2B	0	.0%	2	100.0%				
3A	2	33.3%	4	66.7%				
3B	9	29.0%	22	71.0%				
4	13	31.0%	29	69.0%	3.62	6	0.728	
Stage SCLC								
Limited	1	16.7%	5	83.3%				
Extensive	10	66.7%	5	33.3%	4.295	1	0.038	*
Presence or absence of metastases								
None	19	31.7%	41	68.3%				
Metasases	23	40.4%	34	59.6%	0.958	1	0.343	
Time from diagnosis to POS								
Within 3 weeks	12	40.0%	18	60.0%				
3-6 weeks	2	33.3%	4	66.7%				
6 weeks to 3 months	6	33.3%	12	66.7%				
3-6 months	7	38.9%	11	61.1%				
6-12 months	10	38.5%	16	61.5%				
> 12 months	5	26.3%	14	73.7%	1.19	5	0.946	
Performance status rated by patients								
0-1	19	52.8%	17	47.2%				
2	10	34.5%	19	65.5%				
3-4	13	25.0%	39	75.0%	7.167	2	0.028	*
Diagnosis PS, assessed by doctor								
0-1	21	33.9%	41	66.1%				
2	16	42.1%	22	57.9%				
3-4	3	42.9%	4	57.1%	0.778	2	0.678	
Active anti-cancer treatment								
Yes	28	32.9%	57	67.1%				
No	9	45.0%	11	55.0%	1.032	1	0.313	
Deprivation								
Dep Cat 1-5	20	32.8%	41	67.2%				
Dep cat 6 or 7	22	39.3%	34	60.7%	0.536	1	0.536	
Satisfaction score								
0-4	19	34.5%	36	65.5%				
5-8	0	.0%	1	100.0%				
9-12	0	.0%	0	.0%	na			
GP attendance between clinics								
No	8	36.4%	14	63.6%				
Yes	12	30.0%	28	70.0%	0.263	1	0.777	
Cough								
No	17	51.5%	16	48.5%				
Yes	24	29.3%	58	70.7%	5.08	1	0.032	*
Haemoptysis								
No	36	38.3%	58	61.7%				
Yes	4	21.1%	15	78.9%	2.06	1	0.193	
Cough								
Lower	32	50.0%	32	50.0%				
Higher	9	17.6%	42	82.4%	12.95	1	<0.001	***
Haemoptysis								
Lower	37	34.9%	69	65.1%				
Higher	3	42.9%	4	57.1%	0.18	1	0.697	
Pain								
Lower	26	54.2%	22	45.8%				
Higher	16	23.2%	53	76.8%	11.81	1	0.001	**
Other symptoms								
Lower	33	44.6%	41	55.4%				
Higher	7	17.9%	32	82.1%	7.93	1	0.007	**
Personal anxiety								
Lower	23	46.0%	27	54.0%				
Higher	17	27.0%	46	73.0%	4.41	1	0.048	*
Support network anxiety								
Lower	15	48.4%	16	51.6%				
Higher	26	31.3%	57	68.7%	2.85	1	0.124	
Less ability to share								
Lower	31	37.3%	52	62.7%				
Higher	11	34.4%	21	65.6%	0.09	1	0.831	
Reduced life-worth								
Lower	40	43.5%	52	56.5%				
Higher	2	9.1%	20	90.9%	9.02	1	0.003	**
Reduced self-esteem								
Lower	34	49.3%	35	50.7%				
Higher	8	17.4%	38	82.6%	12.10	1	0.001	**
Information needs								
Lower	36	43.4%	47	56.6%				
Higher	5	16.1%	26	83.9%	7.27	1	0.008	**
Practical needs								
Lower	31	37.8%	51	62.2%				
Higher	11	34.4%	21	65.6%	0.12	1	0.830	
Time wasted								
Lower	40	36.0%	71	64.0%				
Higher	2	50.0%	2	50.0%	0.33	1	0.622	

Table 86: Patients who died within three months of questionnaire completion. Univariate analysis of factors across groups of higher and lower dyspnoea. Percentages are adjusted for missing data. *p<0.05, **p<0.01 and ***p<0.001

The factors identified as significant were patient-rated PS, extent of SCLC, cough, pain, 'other' symptoms, personal anxiety, life-worth, self-esteem and information needs. Significant factors were entered into a backwards logistic regression model to test for independent effects. Extent of SCLC was not entered as this was a subset of all the patients. In addition to these significant variables, additional factors of interest were included in the model: age, gender, presence of metastases and deprivation. Results are shown in Table 87.

						95% CI for Odds Ratios		
	b	SE	Wald	df	p value	Odds Ratio	Lower	Upper
Cough (higher)	1.251	.484	6.687	1	.010	3.493	1.354	9.013
Pain (higher)	1.358	.455	8.909	1	.003	3.887	1.594	9.478
Reduced self-esteem	1.717	.818	4.408	1	.036	5.566	1.121	27.640
Constant	-.845	.381	4.910	1	.027	.430		

R^2=0.212 (Cox and Snell); 0.291 (Nagelkerke) Model X^2=26.22, df=3, p<0.001
Hosmer-Lemeshow test: X^2=3.604, df=5, p=0.608

Table 87: Independent factors associated with higher dyspnoea identified through backwards logistic regression for patients in the last three months of life.

A test of the full model against constant only model was statistically significant (Model X^2=26.22, df=3, p<0.001). Nagelkerke's R^2 of 0.291 indicated that around 29% of variance was explained by the model. Overall prediction success was 72.7% (43.6% for lower dyspnoea and 88.7% for higher dyspnoea). This compares to the null model overall prediction success of 64.5%. Each of the predictors in the final model was significant at the p<0.05 level. As such, higher levels of dyspnoea were independently associated with increased cough, pain and reduced self-esteem. There were no significant effects from the other variables which were excluded from the final model. For a fixed level of cough and pain, a patient with reduced self-esteem was 5.57 (95% CI 1.12-27.64) times more likely to have higher dyspnoea.

11.2 Discussion

Dyspnoea in lung cancer can interfere with physical and psychological functioning.[443] Tanaka et al[443] reported that 'clinical dyspnoea' (breathlessness interfering with activities of daily living) occurred in 55% of ambulatory patients with advanced lung cancer. O'Driscoll et al[442] explored the lung cancer patients' experience of breathlessness and described the strong relationship between this sensation and strongly felt emotions and fears. The language used to describe the sensation of dyspnoea moved between physical descriptors (such as 'chest tightness') to emotional descriptors (such as 'frightened the life out of me…breath is more important than water'). In this qualitative study, patients reported that dyspnoea affected many domains of their

everyday life, including activities of daily living, social activities, being able to leave the house, relationships with family and friends and sexual relations.[442]

The current study demonstrates the high prevalence of dyspnoea in the Stobhill clinic lung cancer population. Dyspnoea was rated as moderate, severe or overwhelming by 50% of patients attending the lung cancer clinic (see Section 6.2.1.1).

In cancer, dyspnoea has been previously reported to be independently associated with lung involvement of cancer[130] (primary site or secondary spread), anxiety,[130, 352] smoking, coexistent airway disease, lung irradiation[351] and reduced survival.[136, 339]
In lung cancer, increased breathlessness has been reported to be associated with a variety of factors, including presence of discrete organic causes,[444] cough,[393, 444] pain,[444] reduced performance status, fatigue, 'coping' ability,[393] anxiety,[355, 445] psychological distress[444, 445] and reduced quality of life.[355332]

In the current study dyspnoea was a highly rated physical symptom: 49.8% of patients overall, 49.4% of newly diagnosed patients and 61.9% of patients in the last three months of life described moderate to overwhelming dyspnoea. Potential predictors of increased dyspnoea (moderate-overwhelming) were explored utilising univariate and multivariate analyses. The main factors associated with increased dyspnoea were reduced PS, increased cough, increased pain and reduced self-esteem. Factors that were not related to dyspnoea level on univariate analyses included gender, age, histology, stage, time from diagnosis, deprivation, active anti-cancer treatment, Glasgow Prognostic Scale and practical needs. Personal anxiety was found to be associated with increased dyspnoea on univariate analysis but not in multivariate analysis.

11.2.1 Performance Status and Dyspnoea

Worse PS was associated with increased dyspnoea in each of the three clinical groupings on univariate analysis. However, on multivariate analysis, a PS of 2 was the only significant predictor of increased dyspnoea and only within the whole clinic population grouping. It has been reported in previous studies that increased breathlessness may adversely affect function, activities of daily living[412, 443] and functional status in lung cancer.[442] Furthermore, there is evidence that targeted clinics to treat breathlessness in the palliative setting can improve both dyspnoea and functional ability in lung cancer patients.[446] Utilising specific breathing exercises,[447, 448] education,

medications[449] (such as opioids and benzodiazepines) and a focused approach to dyspnoea can improve symptom control and quality of life in patients with lung cancer.[446] Smith et al[355] did not find a significant association between PS and dyspnoea on univariate analysis of 127 lung cancer patients, but in their study most patients were PS 0 or 1 with only five patients reported with PS 4 and 14 patients with PS 3. Henoch et al[393] and Tanaka et al[444] reported increased dyspnoea in lung cancer patients with reduced PS. It should also be noted that in the outpatient setting there is likely to be bias against patients with poorer PS and high dyspnoea as they may be less able to attend the clinic. As such, this segment of the population may be underrepresented in any outpatient study.

11.2.2 Other Physical Symptoms and Dyspnoea

Cough and pain were consistently found to be independent predictors of increased dyspnoea in the current study. This was found to be the case on multivariate analysis in each of the clinical groupings. Furthermore, these two physical symptoms were the only two factors left in the model for newly diagnosed patients and comprised two of the three significant factors left in the model for patients in the last three months of life. This finding is in keeping with Tanaka et al[444] who, in a study of 171 consecutive patients with advanced lung cancer, reported that the four independent predictors of increased dyspnoea were pain, cough, psychological distress (anxiety or depression) and presence of an organic cause for dyspnoea (e.g. pleural effusion, lymphangitis, pneumothorax, anaemia, etc). Henoch et al[393] also reported cough as an independent predictor of dyspnoea but did not find an association between pain and dyspnoea. Smith et al[355] reported pain as associated with increased dyspnoea but did not investigate the relationship between cough and dyspnoea.

The association between pain and dyspnoea may be explained by high prevalence of the two symptoms in the lung cancer population, the common link being the lung cancer itself. Lung cancer patients are at increased risk of dyspnoea due to the presence of direct organic causes for breathlessness, and pain is also highly prevalent in lung cancer (see Section 10). However, it can be speculated that a bi-directional causal relationship may exist between these symptoms. In lung cancer, pain is often located in the chest due to local effects of the tumour, invasion of or spread to the ribs, infiltration of inter-costal nerves or invasion or spread to the pleura.[401] It is likely that pain in the chest itself will limit breathing and contribute to the sensation of breathlessness.[444] As such, pain may

be causing dyspnoea. Furthermore, the presence of dyspnoea may affect pain sensitivity by diminishing serotoninergic functions or may decrease sensitivity through the release of endogenous opioids.[444] There may also be a common central link between the symptoms of pain and dyspnoea. Emerging evidence has suggested there may be a common aversive signalling pathway within the brain through which the 'unpleasantness' of symptoms such as pain and dyspnoea is mediated.[414-416] The sensitivity of such a pathway to one symptom may be increased by the presence of another symptom.[414] In the current study, increased dyspnoea was an independent predictor of increased pain in the general clinic population and in patients within the last three months of life. However, this study was not designed to elucidate any relationship between these two symptoms and as such the above must remain speculative.

11.2.3 Psychological Factors and Dyspnoea

The relationship between dyspnoea and anxiety has been described in a variety of settings.[416, 449, 450] Furthermore, addressing anxiety that occurs due to breathlessness, or triggers dyspnoea, is part of dyspnoea management.[449] In the advanced cancer setting, increased dyspnoea has been described in patients who have increased anxiety.[451] In lung cancer studies, the relationship between dyspnoea is less well defined. Most studies reported a positive relationship on univariate analysis, but this did not always remain on multivariate analysis. The situation is complicated by the heterogeneous populations studied, varying phases of the lung cancer journey being reported and the impact of other potential confounding variables. Tanaka et al[444] did describe psychological distress (anxiety or depression) as being an independent predictor of increased dyspnoea in ambulatory lung cancer patients with advanced disease. Henoch et al[393] reported that reduced coping ability was related to increased dyspnoea. They also reported anxiety and depression were associated with increased dyspnoea. However, only coping ability remained in the model after multivariate analysis. Chan et al[445] studied 27 patients with advanced lung cancer to evaluate the possible symptom cluster of anxiety, fatigue and dyspnoea. They reported that there was some evidence for such a cluster but the significant correlations were low in strength. Smith et al[355] also described an increase in dyspnoea reported by patients with a high anxiety trait.

In the current study, increased breathlessness was significantly associated with both increased personal and support network anxiety on univariate analysis in each of the groupings. However, on multivariate analysis, anxiety was not an independent predictor

of dyspnoea. Likewise, on multivariate analysis, increased dyspnoea did not predict increased personal anxiety or support network anxiety in this study (see Section 9). Multivariate analysis is dependent on the factors identified and entered into any model. It does appear that there was an association between increased anxiety and dyspnoea, but this may not be causal or direct. Furthermore, anxiety in lung cancer may be described with relationship to a symptom, the disease itself, treatments or existential fears and concerns. The LCQ question specifically asks 'have you been feeling anxious or worried about your illness or treatment?' This formulation of the question may miss anxiety that is more diffuse or relates to a specific factor other than illness or treatment (e.g. investigations, symptoms, etc).

Increased dyspnoea has been reported in depressed patients with chronic respiratory diseases.[452, 453] Furthermore, in the advanced cancer setting, increased dyspnoea has also been described in patients who have increased depression.[451] In lung cancer, increased risk of depression has been described in patients experiencing higher symptom burden and reduced performance status.[380] Tanaka et al[444] also reported that increased dyspnoea was independently predicted by increased psychological distress (including anxiety and depression). However, a relationship between depression and dyspnoea has not been previously described specifically in lung cancer patients.

In the current study, reduced self-esteem ('do you feel good about yourself?') was an independent predictor of increased breathlessness in the whole clinic population and for those within the last three months of life. Reduced self-esteem was also an independent predictor of increased personal anxiety in each clinical grouping. This finding suggests that reduced self-esteem is a key part of any relationship between increased anxiety and dyspnoea that has been previously described. The association between self-esteem and anxiety is further explored in Section 9. Reduction in feeling life was worthwhile ('have you felt life was worthwhile?') was not associated with either increased anxiety or dyspnoea. It is difficult to make direct comparisons between the LCQ questions and previous studies. The LCQ focuses on self-esteem and life-worth, which are specific components of or related to depression.[375, 454] Reduced self-esteem has been reported to be related to increased depression in population studies[391] and in patients with head and neck cancer.[455] There have been no previous reports evaluating self-esteem and depression in the lung cancer population.

11.2.4 Non-Significant Factors

Previous studies have consistently reported no relationship between dyspnoea and histology, stage of lung cancer, gender, social status and age.[393] There have been some reports of increased dyspnoea in patients receiving radiotherapy.[456] These previous findings are in keeping with the current study. Dyspnoea has previously been identified as a prevalent symptom at diagnosis,[82, 292] during treatment,[174, 283] in the terminal phase[303, 393] and in survivors of lung cancer whom have undergone surgery.[115] These findings are in keeping with the current study, both in prevalence of severe dyspnoea and in absence of a relationship between time from diagnosis and dyspnoea. Despite this symptom prevalence throughout the lung cancer journey, increased breathlessness has also been identified as an adverse prognostic factor in advanced cancer.[136] The current study did find that dyspnoea was an independent predictor of reduced survival in the last three months of life in patients with lung cancer (see Section 8.2.3).

11.3 Conclusions

The high prevalence of dyspnoea in lung cancer has been confirmed in patients attending the Stobhill lung cancer service. This troublesome symptom was not related to demographic factors, the type of lung cancer or the stage of lung cancer journey. Independent predictors of increased dyspnoea were reduced PS, increased cough, increased pain and reduced self-esteem. Full evaluation of an individual's symptom burden is important to identify troublesome symptoms, but particular attention should be paid to identifying increased dyspnoea in patients with any of the above factors. The relationship of anxiety with dyspnoea has been previously described in the cancer setting. The current study did not demonstrate any independent relationship between personal anxiety and dyspnoea. However, reduced self-esteem was associated with increased dyspnoea and this may influence the findings in this study. Dyspnoea is an important symptom in the Stobhill lung cancer population and, when identified, should be evaluated fully for associated factors.

12 Discussion

12.1 Introduction

Patients who are diagnosed with lung cancer face a condition which is likely to be incurable and is associated with increased psychosocial burden,[2, 457, 458] financial implications,[459] high symptom distress[1, 174, 283] and reduced survival.[3] Lung cancer has been associated with greater unmet supportive care needs than other cancers since Weisman's report in 1976.[4] This finding has been confirmed in more recent studies, with lung cancer being identified as an independent predictor of increased physical and psychosocial distress.[175] Despite this, high levels of unmet needs remain in lung cancer patients, particularly psychosocial needs.[11]

In addition to these issues, patients may also receive palliative or curative intent treatments with known toxicities and face decisions which are difficult and provoke anxiety.[180] A recent review of '100 years of lung cancer' failed to make any mention of supportive care needs or symptom control in lung cancer.[19] The introduction of formal supportive and palliative care guidance for lung cancer management has only occurred recently.[275] It is clear that such patients require focused, consistent and structured support from the point of diagnosis and throughout their illnesses. It is not clear how best to provide such support and how best to integrate such support into multidisciplinary care.

This study has evaluated the supportive care needs of patients within the Stobhill lung cancer service, identified key issues, further evaluated these key issues, explored clinical indices for utility in the targeting of supportive care and evaluated patients' views on service provision. This section will discuss the clinical care of lung cancer patients in reference to the stated aims of the project (Section 2).

The development of this project has balanced the service aims of developing an evidence base to inform improvements through clinically useful instruments and evaluation of supportive care needs within the context of the published literature. This balance can be difficult to achieve and has raised the previously discussed methodological issues and limitations (Section 3). Such issues can be considered in the context of internal and external validity.[460] Internal validity refers to how well a study measures what it sets out to measure; external validity refers to how well findings in one

study can be generalised to other groups.[460] There can be a trade off between internal and external validity. For example, in randomised controlled trials the outcomes relate to a highly selected, controlled sample open to participation bias. The resultant outcomes are often clear and well defined but, therefore, less generalisable.[460, 461] Observational studies are often less selected, evaluate more heterogeneous groups and, therefore, outcomes are more generalisable but less defined. The possible biases within this study and the resulting limitations will be further discussed in Section 12.7.[462]

The response and characteristics of the population described in Section 6.1 will be summarised. The discussion within Sections 6-11 will also be summarised and further considered within the context of the stated aims (Section 2). In keeping with Aim 6, recommendations for service improvement and for future work will be discussed in Section 12.8.

12.2 Characteristics and Response of the Stobhill Lung Cancer Service Population

Three hundred and fifty three lung cancer patients attending the Stobhill lung cancer clinic responded within the 30 month long study period. This represents a good response in a service that diagnoses around 130 patients with lung cancer each year.

The characteristics of this population were in keeping with the recent United Kingdom lung cancer national audit[3] (Table 24). The main difference identified was the preponderance of females within this sample. A longer median survival than expected was also identified. In addition, a very high level of deprivation was found in this population.

The majority of patients presented with NSCLC. Advanced disease is common in this population, with over one third of patients having metastatic disease at presentation. In keeping with the out-patient setting, most patients had a performance status of 2 or better at diagnosis. The proportions able to undergo surgical resection also reflect known, national data, as did the percentages of patients receiving other anti-cancer treatments. In keeping with expectations, over half the patients in the current study were aged 70 years or more.

It is of note that there were more females in this sample than males. This is not typical for lung cancer studies but may reflect some participation bias, as well as the increasing national incidence of lung cancers in females[40] and local increases in the incidence of female lung cancer referrals.[189, 190] Gender differences regarding supportive care needs and symptoms in lung cancer have been discussed in the literature and are likely to represent complex dynamics between biological sex and other social factors.[286, 418] Gender differences were controlled for during the multivariate analyses.

The median survival of all patients attending the Stobhill clinic was 11.47 months. This was higher than expected. However, the whole clinic population included those who were under treatment and those attending for routine follow-up after potentially curative treatment. Evaluating the three different clinical groupings in this study allowed this bias to be partly addressed through stratification. When considering newly diagnosed patients, Overall survival from diagnosis in this population was 9.1 months. This is also higher than previously published studies. It is likely that this reflected the out-patient nature of the study population and a selection bias towards longer surviving patients.[460] Direct hospital admission is not an uncommon mode of presentation and diagnosis in lung cancer,[80] and this study would not have included all patients who presented in this way. Some patients who present to hospital would have died and, therefore, never attended the clinic. These patients have not been evaluated and this represents a form of prevalence-incidence selection bias (Neyman bias).[462] Patients who did survive the initial hospital admission may have subsequently attended the clinic beyond six weeks from their diagnosis with lung cancer. These patients would not have been included in the new patient analyses (defined as less than six weeks from diagnosis). It is possible that this has contributed to the observed median survival being greater than expected. Furthermore, those with a poorer performance status and a high symptom burden were less likely to be able to attend an out-patient clinic, and if they did, may have felt less inclined to complete the questionnaire.

There was a marked level of deprivation in the lung cancer patients attending this clinic. Although an increased incidence of lung cancer is associated with deprivation,[52, 333-335] the degree of deprivation in this population is greater than would be anticipated from the literature. However, this was not an unexpected finding given the level of deprivation within the Stobhill Hospital catchment area (Section 6.1). It can be speculated that deprivation may affect both survival[50, 52, 368] and supportive care needs[53]

in cancer patients. However, no differences were found in this population when evaluating survival or supportive care needs between the three most deprived groups and other more affluent patients (see Sections 7 and 8).

12.3 Understanding Lung Cancer

To review the literature regarding symptoms related to lung cancer (Aim 2 and Section 5).

The literature review undertaken within this study confirms that there are unmet physical and psychosocial needs at each stage of the lung cancer journey, including at presentation, at diagnosis, during investigation, during treatment (palliative or curative intent), at the end of life and in survivors (see Section 5). Meeting this aim has allowed a good understanding of the likely symptoms and issues that may be of particular importance in the Stobhill lung cancer population.

Symptoms are dynamic in nature and the distress (or lack of) associated with any given symptom results from a complex interplay of multiple factors[162, 165] (Section 1.5). Furthermore, the concept of symptom burden recognises that multiple symptoms may influence each other and global distress in an equally dynamic fashion.[121, 324] As such, symptoms are individual and subjective. It is recognised that measurement of symptoms is therefore also complex. Furthermore, the choice of instrument to measure any factor will influence the observations made. It has been noted that the reported validity of any instrument designed to measure subjective health issues is limited to describing the instrument *plus* the population studied *plus* the setting of the study *plus* the manner in which the population has been engaged *plus* any error within the study.[463] When utilising such measurement tools, these constraints should be recognised.

12.4 Identifying Unmet Need

To evaluate the prevalence of supportive care needs within Stobhill Hospital's lung cancer multidisciplinary clinic, to assess overall supportive care needs as measured by the Palliative Outcome Scale and to identify the key issues reported by patients in three groupings (Aim 1 and Section 6.2).

Section 6.2 describes the supportive care needs identified using the Lung Cancer Clinic Questionnaire in the Stobhill lung cancer service. In keeping with reported high levels

of need in patients attending lung cancer outpatient clinics,[11-13] more than 90% of patients identified at least one unmet need from the POS questions and at least one active respiratory symptom. Furthermore, over 40% of patients attending the Stobhill lung cancer clinic reported moderate to overwhelming perceived anxiety within their support network (56.9%), moderate to overwhelming personal anxiety (50.8%), moderate to overwhelming dyspnoea (49.8%) and moderate to overwhelming pain (40.8%). These same four issues were reported most often in each of the clinical groupings considered. Therefore, anxiety, pain and dyspnoea have been identified as key issues in this population of lung cancer patients attending the Stobhill outpatient clinic when utilising the LCQ to assess needs.

To evaluate clinical indices used within the Stobhill service to help identify patients with increased supportive care needs overall as measured by POS (Aim 4a and Section 7).

In Scotland, although the incidence of lung cancer has peaked, there has been an effort to improve time from presentation to treatment in recent years.[37, 207, 464] With the increasing complexity of investigations and treatment options, there is increasing pressure on lung cancer services, and this can lead to reduced time available for each individual patient.[465] Palliative and supportive care services in Scotland are also providing increased levels of care to a broader range of patients and higher numbers of patients.[466, 467] It is clear that care must be appropriately targeted to most efficiently deploy resources in meeting these challenges.[277]

The Palliative Outcome Scale can be utilised to identify individuals' supportive care needs in a variety of settings. In keeping with Aim 4a, considered here are, firstly, the use of the adapted POS questions within the LCQ to systematically assess individuals' supportive care needs and, secondly, whether or not clinically relevant indices could allow patients with increased needs to be identified more readily.

Patients may well have unmet needs which have not been identified or met despite attending a lung cancer clinic.[11, 216, 350] Steele et al[14] described that many lung cancer patients do not volunteer unmet needs as they feel they have an ability to manage, assume symptoms are part of the disease and cannot be altered, utilise their own existing support networks, feel staff are already too busy and/or are unaware that help is

available. Despite this, most patients would like to take up offers of help with supportive care needs.[14, 468] Systematic assessment of symptoms and needs have been demonstrated to be more effective in identifying unresolved problems than traditional clinic reviews.[276] The only randomised controlled trial to examine the use of a protocol driven, systematic assessment in lung cancer care showed that such an approach, delivered by a specialist nurse, identified more issues, provided more palliative radiotherapy and allowed more patients to die at home but had no effect on overall survival.[264] The Palliative Outcome Scale is a tool which provides patient-rated outcome measures and allows a systematic evaluation of supportive care needs.[147, 204] POS has been successfully adapted already to suit settings different from hospice only.[217, 221]

The experience in the Stobhill lung cancer clinic demonstrates that POS can be successfully incorporated into clinical care within a busy outpatient clinic and obtain information regarding supportive care needs of individuals and clinic populations. POS population data may further allow service structures to be reviewed and improved to allow identified needs to be addressed.

POS can highlight specific issues in physical, psychological and social domains for each individual patient. As a patient-reported outcome measure, POS has the benefit of describing the main issues from the perspective of the patient themselves. This allows issues, often psychosocial problems, not often elicited and managed by medical models of care[11] to be highlighted. However, POS does not detail any of the problems reported (e.g. does not identify pain type or cause).

Despite this, in the context of clinical care, the use of POS as a screening tool is attractive. It compares well to other instruments and maintains a broad range of supportive care domains while retaining brevity (Table 6). Identified issues could then be addressed clinically or further assessed using more specific validated tools, (e.g. The Brief Pain Inventory[469, 470] for pain or the Hospital Anxiety and Depression Scale[310] for anxiety).

The reported supportive care needs within this study are in keeping with other studies utilising POS. Furthermore, the findings are in keeping with symptom and need prevalence studies utilising many other tools used in symptom distress screening,

supportive care needs evaluation and quality of life studies (see Sections 6.2 and 7-11). These findings support the utility of POS within the LCQ as a useful clinical tool, a valid method for service analysis and a potentially helpful tool for research into supportive care needs. However, there was no formal testing of the LCQ undertaken for reliability or face validity (section 12.3.2) and, as such, the comparisons must be limited in scope. This is further discussed in Section 12.7.

In Section 7, possible predictors of increased supportive care needs (POS>10) were evaluated. The factors identified within the three groupings are tabulated below.

All patients		Newly Diagnosed patients		Patients within 3 months of death	
Univariate	Multivariate	Univariate	Multivariate	Univariate	Multivariate
Poorer PS Younger age Diagnosis Treatment Resp score Review frequency Stage (NSCLC)	Poorer PS Younger age Resp. score Cough Haemoptysis	Poorer PS Younger age Resp. score	Poorer PS Younger Age	Poorer PS Resp. score	Poorer PS Dyspnoea Haemoptysis

Table 88: Summarised significant univariate associations and independent predictors of increased supportive care needs (Section 7).

It is of note that having a POS>10 was independently associated with reduced performance status in each of the groupings studied: general clinic population, newly diagnosed patients and patients in the last three months of life. ECOG PS is used extensively within cancer management within the UK,[10] is used as part of inclusion criteria for clinical trials[405, 471] and is integral to decision making within the Stobhill lung cancer service. As such, this clinical scale could be further utilised to identify patients who may benefit from greater supportive care provision.

Importantly, there was no independent relationship between supportive care needs and type of lung cancer, stage of lung cancer, time from diagnosis, gender or deprivation level (see Section 7). This finding is supportive of the concept of integrating supportive care throughout the lung cancer journey (see Section 1.4.7). Therefore, it is important to try and identify patients in need by recognising the associations of high supportive care needs. However, systematic screening assessment may be necessary to identify all needs.

Recommendation 1: Supportive care needs should be systematically assessed within the Stobhill lung cancer services from the point of diagnosis throughout the lung cancer journey.

12.4.1 Anxiety – A Key Supportive Care Need

To evaluate clinical indices used within the Stobhill service to help identify patients with increased risk of key supportive care needs: anxiety (Aim 4c and Section 9).

Anxiety has been identified as a key supportive care issue in the Stobhill lung cancer service. Anxiety is known to be common within the lung cancer population, is often underestimated and impacts significantly on the quality of life of patients.[2, 13, 107, 168, 176, 369] Within the lung cancer clinic population in the current study, around half of patients reported moderate, severe or overwhelming personal anxiety. Personal anxiety appeared higher in newly diagnosed patients and those within three months of death than in the general clinic population. In keeping with previous studies utilising POS, more patients reported perception of high levels of anxiety in their support networks than higher levels of personal anxiety (see Section 9). In Section 9, possible predictors of increased personal and support network anxiety were evaluated. The significant associations and predictive factors identified within the three groupings are tabulated below.

All patients		Newly Diagnosed patients		Patients within 3 months of death	
Univariate	Multivariate	Univariate	Multivariate	Univariate	Multivariate
Poorer PS Younger age Time from diagnosis GP attendance Dyspnoea Cough Haemoptysis Pain Other symptoms Supporter anxiety Low self-esteem Information needs Practical needs	**Model 1:** Supporter anxiety Cough Low self-esteem **Model 2:** Poorer PS Cough Low self-esteem Time from diagnosis <6months	Poorer PS Younger age Time from diagnosis Dyspnoea Cough Pain Other symptoms Supporter anxiety Low self-esteem Low life-worth	**Model 1:** Poorer PS Supporter anxiety Low self-worth **Model 2:** Cough Low self-esteem	Dyspnoea Cough Other symptoms Supporter anxiety Low self-worth Low self-esteem	**Model 1:** Supporter anxiety Low self-esteem **Model 2:** Low self:-esteem

Table 89: Summarised significant univariate associations and independent predictors of increased personal anxiety (Section 9).

All patients		Newly Diagnosed patients		Patients within 3 months of death	
Univariate	Multivariate	Univariate	Multivariate	Univariate	Multivariate
Poorer PS Younger age Time from diagnosis Dyspnoea Cough Haemoptysis Pain Other symptoms Personal anxiety Low self-esteem Low self-worth Reduced ability to share Information needs Practical needs	**Model 1:** Poorer PS Metastases present Time from diagnosis < 6 months Personal anxiety **Model 2:** Poorer PS Metastases present Haemoptysis Low self-esteem Time from diagnosis <6 months	Poorer PS Time from diagnosis Dyspnoea Cough Haemoptysis Pain Personal anxiety Low self-esteem	**Model 1:** Pain Personal anxiety **Model 2:** Cough Pain Low self-esteem	Poorer PS Cough Other symptoms Personal anxiety Low self-esteem Information needs	**Model 1:** Personal anxiety Information needs **Model 2:** Other symptoms Low self-esteem Information needs

Table 90: Summarised significant univariate associations and independent predictors of increased perceived support network anxiety (Section 9).

A strong relationship between personal anxiety and levels of anxiety perceived in the support network was demonstrated. However, despite these high levels of anxiety, most patients reported they felt able to share their feelings with others if they wished. This is important as possible models of care could include enabling existent support networks to address anxiety and other issues. There was no evidence that male or female patients were likely to be more anxious. No relationship was found between anxiety and age or presence of active anticancer treatments. Reduced self-esteem was identified as an independent predictor of increased anxiety in this study. This is of particular importance, as both anxiety and reduced self-esteem can be addressed through well established psychotherapeutic methods.[371, 392] PS was identified as a key predictor of increased anxiety in the general clinic population and newly diagnosed patients.

Recommendation 2: Anxiety is a key issue within the Stobhill lung cancer population. This issue should be assessed systematically to allow identification and further management at all phases of the lung cancer journey

Recommendation 3: To address anxiety and worry, Stobhill lung cancer services should explore ways in which to further support patients and their support networks.

12.4.2 Pain in Lung Cancer

To evaluate clinical indices used within the Stobhill service to help identify patients with increased risk of key supportive care needs: pain (Aim 4c and Section 10).

Pain in lung cancer has been well described in a recent review by Potter et al.[401] The current study confirms that there was a high prevalence of uncontrolled pain in lung cancer patients attending the Stobhill outpatient lung cancer clinic. Around four in ten patients rated pain as moderate, severe or overwhelming (see Section 10). POS does not evaluate pain in any great detail so it is not possible to identify pain type, frequency or aetiology from this data. However, POS does assess the prevalence of pain that is disturbing the patient's routine activities. The significant associations and predictive factors identified within the three groupings are tabulated below.

All patients		Newly Diagnosed patients		Patients within 3 months of death	
Univariate	Multivariate	Univariate	Multivariate	Univariate	Multivariate
Poorer PS Younger age Dyspnoea Cough Other symptoms Personal anxiety Supporter anxiety Ability to share Low self-esteem Information needs Practical needs Time use	Poorer PS Younger age Dyspnoea Other symptoms	Poorer PS Dyspnoea Other symptoms Personal anxiety Supporter anxiety Low self-esteem Information needs	Poorer PS Younger age Other symptoms Information needs	Dyspnoea Haemoptysis Other symptoms	Dyspnoea Other symptoms

Table 91: Summarised significant univariate associations and independent predictors of increased pain (Section 10).

There was no independent relationship identified between increased pain and gender, stage, histology, deprivation, anxiety, depression or presence of active anti-cancer treatments. Predictive factors for increased pain were poorer PS, younger age, dyspnoea and 'other' symptoms. In newly diagnosed patients, unmet information needs were also associated with increased pain. Again it was noted that poorer PS was a key predictor of increased pain.

Recommendation 4: Pain is a key issue within the Stobhill lung cancer population. Pain should be assessed systematically to allow identification and further management at all phases of the lung cancer journey. In particular, those with a poorer performance status should have pain assessed within the clinic.

12.4.3 Dyspnoea in Lung Cancer

To evaluate clinical indices used within the Stobhill service to help identify patients with increased risk of key supportive care needs: dyspnoea (Aim 4c and Section 11).

It can be expected, and has been demonstrated, that dyspnoea is a prominent symptom in lung cancer. Tanaka et al[444] recently described a variety of correlates with dyspnoea in lung cancer patients. This study emphasised that 'clinical dyspnoea' is a multi-factorial experience[441] and is best considered and managed with that understanding.[442, 446, 447] In the current study, dyspnoea was rated as moderate, severe or overwhelming by five in ten patients attending the Stobhill lung cancer clinic. Furthermore, 61.9% of patients in the last three months of life reported moderate to overwhelming breathlessness. The significant associations and predictive factors identified within the three groupings are tabulated below.

All patients		Newly Diagnosed patients		Patients within 3 months of death	
Univariate	Multivariate	Univariate	Multivariate	Univariate	Multivariate
Poorer PS Cough Pain Other symptoms Personal anxiety Supporter anxiety Low self-esteem Low life-worth Information needs	Poorer PS Cough Pain Low self-esteem	Poorer PS Cough Pain Other symptoms Personal anxiety Supporter anxiety Low self-esteem GP attendance	Cough Pain	Poorer PS Histology Stage of SCLC Cough Pain Other symptoms Personal anxiety Low self-esteem Low self-worth Information needs GP attendance	Cough Pain Low self-esteem

Table 92: Summarised significant univariate associations and independent predictors of increased dyspnoea (Section 11).

Through logistic regression, the main factors identified that predicted increased dyspnoea were reduced PS, increased cough, increased pain and reduced self-esteem. It was of note that there was no relationship between increased dyspnoea and gender, age, histology, stage, time from diagnosis, deprivation, active anti-cancer treatment or practical needs. Personal anxiety (about illness or treatment) was associated with increased breathlessness on univariate analysis but not multivariate analysis. PS may therefore be a useful predictor of increased dyspnoea.

Recommendation 5: Dyspnoea is a key issue within the Stobhill lung cancer population. Dyspnoea should be assessed systematically to allow identification and further management at all phases of the lung cancer journey. In particular, those with a poorer performance status should have dyspnoea assessed within the clinic.

12.5 Understanding the Urgency

In any life-limiting condition, prognosis plays an important role in decision-making for patients and healthcare staff. When a prognosis is likely to be short, it is likely that treatments with major toxicities would be avoided and a greater focus placed upon quality of life. Symptom distress and reduced quality of life have both been previously associated with reduced life expectancy.[1, 183, 309] Lung cancer patients often present with incurable disease and have a short life expectancy from the point of diagnosis. It would be useful to be able to identify individual patients with shorter survival and higher supportive care needs early within the disease journey. In this way efficient, effective supportive care could be targeted and provided more rapidly.

12.5.1 Survival and Supportive Care Needs in Lung Cancer

To evaluate clinical indices used within the Stobhill service to help identify patients with a reduced survival (Aim 4b and Section 8)

Unmet supportive care needs have been demonstrated at specific junctures in the cancer journey: in particular, at time of diagnosis, investigation, discharge from clinics, point of recurrence and the terminal phase.[180] It is not clear whether there is any association between increased supportive care needs and reduced survival.[369] If patients with shorter survival also have higher supportive care needs, then there is a greater impetus for increased speed of care provision. Conversely, it may be that all patients, irrespective of expected survival, could benefit from supportive care. This would be in keeping with suggested models of integrating supportive care throughout the disease journey. POS score and other known adverse prognostic factors were evaluated in Section 8. The significant associated and predictive factors identified within the three groupings are tabulated below.

All patients		Newly Diagnosed patients		Patients within 3 months of death	
Univariate	Multivariate	Univariate	Multivariate	Univariate	Multivariate
Poorer PS Histology (SCLC) Metastases present Weight loss POS >10 No treatment	Poorer PS Metastases present Weight loss	Poorer PS Metastases present POS >10	Metastases present	Dyspnoea Pain Personal anxiety Increased ability to share	Dyspnoea Pain Increased ability to share

Table 93: Summarised significant univariate associations and independent predictors of reduced survival (Section 8).

The adverse prognostic factors identified in the Stobhill lung cancer population are in keeping with the known main determinants of survival.[100] It is of interest to note that the physical factors, such as performance status and metastases, were not independent factors in the last three months. This is in keeping with the reported significance of symptoms in the terminal phase of many cancers.[136, 339]

Regarding supportive care needs, there was a significant association with increased POS scores and reduced survival from the time of questionnaire completion on univariate analysis. However, on multivariate analysis (controlling for PS, stage and other factors) there was no independent relationship between POS and survival. Given the high levels of unmet need reported above, this finding supports models of supportive care that are integrated throughout the lung cancer journey. In Section 7, the close relationship between poorer PS and increased supportive care needs was also identified. Given the strong relationship between poorer PS and reduced survival, it is understandable that POS did not add further independent information regarding survival. Despite this, the triad of reduced function, increased supportive care needs and reduced survival may be a useful aid to lung cancer services in targeting and timing referrals to supportive care teams for individual patients. Clearly, care should be prompt for those in whom time is short.

Recommendation 6: Supportive care should not only be aimed at those near the end of life but should be available to all patients throughout the whole of the lung cancer journey.

Recommendation 7: Known adverse prognostic factors may be used to prioritise timing of care and enable appropriate decision making. However, further work is necessary to define the role of these factors, in particular performance status.

12.6 Evaluate Service and Preferences

To review the literature regarding the current guidance and evidence for follow-up in lung cancer (Aim 3 and Section 4).

The literature review undertaken within this study confirms that the evidence for follow-up in lung cancer is poor. There is great variability within the guidance and there is little emphasis on supportive care issues. Despite this, follow-up is likely to be a useful platform for the delivery of supportive care (see Section 4). Meeting this aim has allowed a good understanding of the current evidence and practices of follow-up in the lung cancer setting. It would be useful to develop evidenced based follow-up models in the future that also take into account patients' wishes and needs.

12.6.1 Current Service Use

To evaluate the Stobhill lung cancer service regarding service usage (Aim 5a and Section 6.1).

The median review interval at the Stobhill clinic is 11 weeks (Table 17). This, however, represents a wide range of types of review appointment, including those under active treatment, those receiving supportive care and those who have received potentially curative treatments. The majority of patients (70.5%) attending the Stobhill lung cancer clinic reported no new or changing symptoms within the interval between review appointments. The majority of studies evaluating follow-up in lung cancer have reported that scheduled appointments often do not identify new or changing symptoms. In contrast, unscheduled appointments are almost always triggered by symptoms (Section 4). In the last three months of life more patients did report active symptoms between appointments (43%). In keeping with these findings, attendance at the general practioner between appointments was low overall (21.2%) but increased in the last three months of life (33.1%). Edmonds reported that within the last year of life the majority of patients with lung cancer (52%) attended their general practioner more than ten times (ranging from never to greater than 20 times).[178] Murray et al[180] reported that discharge

from hospital services to the care of community services can leave patients feeling anxious and uncertain.

Although there are well documented strengths of multidisciplinary team working, there is a risk of professional overload for patients. This may be through overuse of the patient's time or seeing too many health care professionals, resulting in repetition of assessment and care.[70, 223, 332, 343, 472] Within the Stobhill lung cancer service, the majority of patients (81.4%) reported that they did not feel they were seeing too many healthcare professionals, and a similar proportion (81.3%) felt none of their time had been wasted through healthcare attendances. Although these findings are encouraging, it is likely that answers to these questions may be biased towards positive responses. Similar to the positive skew often found in satisfaction studies,[236, 237, 343] patients may feel a sense of gratitude or dependence upon the clinical service and, therefore, limit critical comment. Seen in this light, the fact that 20% of patients reported some issues with time use or number of professionals seen should be considered in any future development of lung cancer services within Stobhill.

Palliative care services play an active role within the Stobhill lung cancer service. In this study, documented referrals to palliative care were higher in the last three months of life (Section 6). It may be that specialist advice was more necessary in this group of patients and that many of the referrals could have been for end of life care. It may also be that referrals were made by phone or through the multidisciplinary meeting and were not documented within the notes. However, given that supportive care needs are apparent throughout the lung cancer journey, this may represent underuse of palliative care services at earlier phases. If this is the case, then it may reflect concerns of appropriateness of referral, patients' reluctance to be referred due to stigma or misperceptions over palliative care's role outwith end of life care.[473] It is of note that, in a study of early palliative care in patients with metastatic NSCLC, Temel et al[474] found early palliative care involvement led to significant improvements in both quality of life and mood. Furthermore, patients receiving palliative care input had less aggressive therapies at the end of life but longer survival.[266, 475]

Recommendation 8: Stobhill lung cancer services should consider the structure and mechanisms of supportive care provision to ensure timely and effective support.

12.6.2 Patients' Satisfaction with the Current Service

To evaluate the Stobhill lung cancer service regarding patients' satisfaction with the service (Aim 5b and Section 6).

The measurement of satisfaction is promoted by the Scottish Government as an important way of engaging patients' views on the quality of service provision.[230] There are difficulties regarding the use of this poorly defined and poorly understood measure (Section 3). One of the main issues relates to the common finding that patients report high satisfaction with services they receive. This almost blanket positive response has been critiqued as measuring something other than true satisfaction: a feeling of gratitude to the service, a dependence upon the service and fear of removal or an unwillingness to be critical.[236, 241] As such, it has been suggested that responses of dissatisfaction should be taken more seriously.[236] It has been suggested that satisfaction evaluation is not useful at all; however, the definition and theory underpinning satisfaction evaluation has improved over the last decade through such work. Furthermore, it could be argued that in asking for service assessment from patients in a systematic way, a more open dialogue between patients and service providers could be promoted in time.

In this study, high levels of satisfaction were reported regarding how the diagnosis was given, the investigation process and the current follow-up arrangements. The latter of these relates well to the finding that most patients would like to continue with the current follow-up structure. There were increased numbers of patients reporting dissatisfaction when considering those in the last three months of life. This may reflect increased distress as they enter the terminal phase of their illness or it may be that service improvement is required to meet the needs of this patient group.

Around one third of patients attending the clinic reported not receiving the level of information they wished. This is an issue that should be addressed and may link to the high levels of anxiety identified.

Recommendation 9: Stobhill lung cancer services should continue to involve patients in service evaluation. This should include a measure of quality or satisfaction rated from the patient's point of view.

Recommendation 10: Information should be available to all patients and communicated in a sensitive and paced manner.

12.6.3 Follow-up: Patients' Understanding and Preferences

To evaluate the Stobhill lung cancer service regarding patients' understanding of the follow-up provision and patients' preferences for follow-up (Aim 5c-d and Section 6).

The role of supportive care has not been emphasised in the care of lung cancer,[19] and its place in follow-up has not been clearly defined. There remain questions regarding the utility of follow-up, its cost-effectiveness, optimal type of follow-up structure, who should provide follow-up, what type of follow-up is wished for by patients and the place of supportive care in follow-up (see Section 6).

The current study demonstrates the high prevalence of unmet needs in this population of ambulatory lung cancer outpatients with reduced life expectancy. The challenge of meeting these needs and providing accessible, equitable care is beginning to be discussed within national guidelines.[277] Different models of care have been suggested, including on-going medical follow-up, nurse-led follow-up, open access clinics with general practioner-led follow-up, integration of palliative care services into multidisciplinary clinics and utilising these different models of follow-up through active MDT decision-making for individuals at different stages of their journey. There is a lack of knowledge regarding patients' wishes and preferences for follow-up (see Sections 4 and 6).

The British Thoracic Society's guidelines do state that patients should know who is in charge of their care.[69] In the Stobhill lung cancer service, a notable proportion (10%) of patients were 'uncertain' as to who was co-ordinating their care. Furthermore, there was a wide variation in who patients thought was in charge. The lead clinician is likely to change throughout the lung cancer journey and this may be reflected in the varied responses. However, in keeping with the guidance, it should be clear both who is in charge and who to contact regarding care issues.

When asked about models of follow-up, the majority of patients preferred to continue with routine MDT clinic follow-up rather than GP-led follow-up (with open access return) or hospital-based, specialist nurse-led follow-up. This finding is common in

surveys of patient preference, but in studies which allow patients to experience nurse-led clinics there is also high a level of satisfaction reported (see Section 6.3).[223, 264, 265, 476] It does appear that a variety of models of care would be acceptable or preferred by different patients. This range of preference is again in keeping with the varied clinical priorities at different phases of the lung cancer journey. It is also in keeping with the British Thoracic Society model of follow-up[277] which advocates several different tracks of care should be available to meet individual needs (Figure 7).

Patients may also be able to draw on their own resources and support network to meet needs. If this is the case, then the role of supportive care services may be best extended to empower and sustain the existing support network. In the current study, most patients felt able to share worries and concerns with somebody (see Section 6.2). This may be one method of meeting need within limited resources. However, it has been clearly demonstrated that patients face lung cancer along with their support network and have worries and concerns that relate to their families and significant others (Section 9). The recognition that patients face illness within the context of a support network, and that the diagnosis of lung cancer can affect carers and families, has led to the recognition that proactive supportive care should be extended to families and significant others.[384] Such models of care have a low evidence base but are now beginning to be studied and implemented.

Recommendation 11: Stobhill lung cancer services should offer a range of follow-up models including clinic-based care, nurse-led care and community-based care. The multidisciplinary team and patient's wishes should drive the choice of follow-up.

Recommendation 12: All patients attending the Stobhill lung cancer clinic should know who is in charge of their care and whom to contact for advice or support.

12.7 Limitations of this Study

In 1979, David Sackett[462] catalogued 35 biases that can occur in research. These can be grouped under three main headings: selection bias, information bias and confounding.[460] Selection bias relates to factors which influence the membership of the population being studied including participation bias, selection bias and non-respondent bias. Information bias relates to factors which influence the response of participants (such as leading

questions, differing modes of questioning or dependence on clinical service being evaluated) and recall bias. Confounding relates to other factors blurring effects. In this case, it may be that one or more factors influence outcome indirectly through interactions or is simply a co-occurrence rather than part of a causative chain. One example of this would be the identification of cigarette lighters causing lung cancer through a correlation study. In this example, it is known that the smoking of cigarettes is the causative factor and the cigarette lighter is only associated by being part of the process of smoking.

12.7.1 Selection Bias

This study was conducted in a single centre and, thus, portrays a site-specific experience. Within this sample there were particular population characteristics that suggested selection bias and may limit generalisation of the findings.

As discussed in Section 6, the population described had a higher median survival than expected, perhaps reflecting some participation bias towards survivors and the ambulatory outpatient population. The preponderance of females within this population may also have affected the responses obtained. These issues may have affected the prevalence of issues reported and univariate associations described. However, the multivariate regressions were performed controlling for the influence of both these factors.

There was a high level of deprivation in the patient catchment area for the study, and this may have influenced the type of supportive care needs reported although it did not affect the overall POS score. The Stobhill catchment area covers a population of more than 200,000 people within the North of Glasgow and part of East Dumbartonshire. This population includes many of the most deprived people in Scotland, with Glasgow City containing almost half (48%) of the 15% most deprived local populations in Scotland.[188] Although this could be considered as a limitation, it can also be seen as a strength of this study. As outlined previously, Glasgow has the highest incidence of lung cancer and the highest lung cancer-related death rate in Scotland. This places Glasgow as a lead in lung cancer experience within the United Kingdom. In global terms, Scotland has one of the highest incidences of lung cancer worldwide. Therefore, the evaluation of supportive care needs within the Stobhill service is likely to provide

valuable insights that could aid service improvement for lung cancer patients no only within but also outwith this catchment area.

12.7.2 Information Bias

Within this study, POS questions were adapted and incorporated within the Lung cancer questionnaire. The reasons for this have been outlined within Section 3 and were driven by the wish to minimise questionnaire burden and retain an instrument that was clinically useful. This may have reduced the validity and reliability of the instrument.[477]

There are several forms of validity that can be assessed for any health measurement instrument. Face validity evaluates whether the tool makes sense and is generally obtained through user groups or experts making judgements on each item.[477] Content validity is the judgement of a group of experts as to whether the instrument adequately covers the areas to be measured.[193] Construct validity relates to assessing whether the tool relates to the underlying theory, what it actually measures and what does it not measure. Some statistical processes can be used to aid this assessment (e.g. factorial analysis).[477] Concurrent validity compares the tool to other validated tools and measures the level of agreement. This requires the index tool to be well validated in a similar population and context. It has also been suggested that new tools should differ from previous tools or there is no value in the new development.[463] Conversely, discriminate validity assesses to what degree the tool differs from other instruments or what items within the tool differ.[477]

Reliability can be considered as relating to internal consistency and test-retest reliability. Internal consistency is assessed through measurement of the variance within item responses as a proportion of the variance between respondents. This can be measured statistically through different methods (e.g. Cronbach's alpha).[463] Test-retest reliability refers to how stable the results from the tool are over time. It has been noted that this type of reliability may not be suitable when considering dynamic variables such as symptoms.[477]

Although the Palliative Outcome Scale is a validated instrument, the adaptations and addition of questions to construct the lung cancer questionnaire will have influenced the responses given. This is a form of informational bias. There were some clear influences on the POS responses as a result of adding questions related to respiratory symptoms.

This was likely to reduce the number of patients who report 'other' symptoms (i.e. they would no longer report cough, dyspnoea or haemoptysis in this section). Despite this, internal consistency did remain high in the POS items. However, less clear item interactions may have occurred within this study. Although POS has been used in an adapted form for other studies, for future work these adaptations would require an assessment of validity. The staged adaptation of adding satisfaction questions in years two and three may also have influenced responses. However, there were no significant differences between summated POS score or questionnaire items completed in year one compared to years two and three. Finally, for patients who completed more than one questionnaire, this may have influenced the responses obtained. Having seen the questions previously could alter scoring in either direction through multiple different mechanisms. This may have affected the results obtained for patients within the last three months of life.

The alteration of the assessed period from three days to four weeks may also have influenced the findings of this study. The aim of this was to match the out-patient environment, to assess issues that were persistent and to filter acute issues. This may have altered some responses by introducing the need to remember issues. It has been reported that the description of symptoms such as pain can be influenced by memory and pain itself can influence ability to remember.[478]

Another approach to this study could have been to use a battery of validated tools to address all of the points of interest. Although the process of questionnaire validation itself has been critiqued as being essentially subjective,[463] validation may have allowed comparisons of similar items to assess for external validity of POS in this population. However, it was not feasible to achieve full validation of the Lung Cancer Clinic Questionnaire within the context of this busy clinic in terms of time use, resources available and considering the risk of questionnaire fatigue. Although validated lung cancer specific tools are available for gaining information regarding some of the issues evaluated, there is no single tool that addresses all of these issues. Combinations of validated tools could be open to the same critique of unknown interactions between items and possible reduced validity.[463] In addition, respondent burden has been reported to relate to longevity of survey, repetition of questions and perceived irrelevance of questions.[479, 480]

12.7.3 Confounders

It is possible to try and control for confounding variables through a process of restriction (i.e. patient selection through selection criteria which may limit the scope of conclusions), matching in case-control studies (which can be complex if multiple variables matched and these variables cannot be analysed for effect) or stratification (i.e. *post hoc* analysis using statistical techniques to control for factors). This study was restricted to lung cancer patients attending the Stobhill lung cancer clinic. No matching of cases and controls was undertaken but stratification was used to assess different groups of patients. The analysis was phased as descriptive, univariate and multivariate. The multivariate approach allowed for control of confounding variables. However, it is not possible to control for all confounders, and this is apparent because logistic regressions only explained a proportion of the variance in prediction of the outcome.

Accepting these limitations of the current study and understanding some of the likely biases within it are important. However, it is also worth noting that approaches to clinically based evaluation can vary from a flexible design[481] (allowing conditions and evolving issues to inform methodology) to a highly controlled, selected and randomised trial.[481] Information gained from different approaches should be viewed in the context of the respective advantages and disadvantages of each method; nonetheless, each form retains value and can inform improvement.

12.8 Future Work

Meeting the supportive care needs of lung cancer patients remains a challenge and currently lacks a strong evidence base from which to proceed. Recent developments in lung cancer management include advances in anti-cancer treatment options (including second and third line treatments), recognition of the need for supportive care and delivering care using a multidisciplinary approach. It is unfortunate that many of these developments have been introduced without assessing efficacy, efficiency and superiority compared to existent care.[70] This study has established a high level of unmet need within the Stobhill lung cancer clinic. However, further study and development is necessary to understand how best to provide care in meeting those needs. Several recommendations, detailed below, have been made from this study.

Recommendation 1: Supportive care needs should be systematically assessed within the Stobhill lung cancer services from the point of diagnosis throughout the lung cancer journey.

Recommendation 2: Anxiety is a key issue within the Stobhill lung cancer population. This issue should be assessed systematically to allow identification and further management at all phases of the lung cancer journey

Recommendation 3: To address anxiety and worry, Stobhill lung cancer services should explore ways in which to further support patients and their support networks.

Recommendation 4: Pain is a key issue within the Stobhill lung cancer population. Pain should be assessed systematically to allow identification and further management at all phases of the lung cancer journey. In particular, those with a poorer performance status should have pain assessed within the clinic.

Recommendation 5: Dyspnoea is a key issue within the Stobhill lung cancer population. Dyspnoea should be assessed systematically to allow identification and further management at all phases of the lung cancer journey. In particular, those with a poorer performance status should have dyspnoea assessed within the clinic.

Recommendation 6: Supportive care should not only be aimed at those near the end of life but should be available to all patients throughout the whole of the lung cancer journey.

Recommendation 7: Known adverse prognostic factors may be used to prioritise timing of care and enable appropriate decision making. However, further work is necessary to define the role of these factors, in particular performance status.

Recommendation 8: Stobhill lung cancer services should consider the structure and mechanisms of supportive care provision to ensure timely and effective support.

Recommendation 9: Stobhill lung cancer services should continue to involve patients in service evaluation. This should include a measure of quality or satisfaction rated from the patient's point of view.

Recommendation 10: Information should be available to patients and communicated in a sensitive and paced manner.

Recommendation 11: Stobhill lung cancer services should offer a range of follow-up models including clinic-based care, nurse-led care and community-based care. The multidisciplinary team and patients' wishes should drive the choice of follow-up.

Recommendation 12: All patients attending the Stobhill lung cancer clinic should know who is in charge of their care and whom to contact for advice or support.

12.8.1 Service Development

The ongoing use of a supportive care need instrument within the Stobhill lung cancer clinic is recommended to allow systematic assessment of need. This tool could continue to be the Palliative Outcome Scale or another lung cancer specific instrument. It is important that this tool remains clinically viable in terms of resource and time available. However, it may add to future evaluations if the instrument was used in its validated form or, if adaptations are made, these are fully validated.

The key issues of anxiety, pain and dyspnoea could be addressed through focusing of current resources. The role of the specialist lung cancer nurse is likely to be pivotal, and formal links between this person and palliative care services may streamline approaches.

The role of support in tackling anxiety has been well established. Furthermore, supporting carers may add benefit.[482] The formation of a support group within Stobhill may help tackle this issue and this has now been established. Lung cancer is a condition that is very likely to cause anxiety. It is noted that anxiety is increased at times in the journey when patients are likely to be meeting healthcare professionals. It is vital that these professionals do not add to anxiety through poor interaction and communication. The British Thoracic Society guidance on communication[394] in lung cancer should be made available in the clinic, and staff could attend communication courses to improve skills. This may enable more information to be shared with patients in a sensitive and paced manner.

Patient education regarding non-pharmacological techniques to control breathlessness may be advantageous and help address dyspnoea. This may be provided by clinic nursing staff or through referral to specialist palliative care services [441, 446]

Cancer pain can often be controlled utilising the analgesic ladder.[402] Pain, and the cause of pain, must first be identified before it can be managed. The ongoing use of a screening tool could be augmented by a more detailed assessment through a pain-specific instrument. Education regarding pain control should be provided to staff within the clinic. For pain that is not controlled by this approach, a clear and efficient referral pathway to palliative care services could be established.

12.8.2 Research and Further Work

Complex, multi-modal supportive care measures can be difficult to evaluate, but there is a move to attempt clearer definitions of 'best supportive care' and 'standard care' within cancer trials.[140] A better understanding of the cancer journey for different tumour types and treatment pathways may allow the development and testing of tumour-specific models of care. In lung cancer, such models of care will benefit from the improved understanding of symptom distress,[162, 309] the pathophysiology of symptoms[401] and effective palliative therapies.[483] However, research into this area remains at a low level and future work is required to increase the knowledge base to allow the development of lung cancer care.

Although patients prefer the option of hospital-based clinics, it is not clear that this is the best way of meeting need. Possible options for follow-up models include hospital-based interval assessment, home-based interval assessment or perhaps real time assessment for selected patients utilising newer technology.[484] There is a need for adequately powered randomised controlled trials to investigate both models of care and specific supportive care interventions.

The key issues of anxiety, pain and dyspnoea in lung cancer patients merit further investigation. Understanding potential predictors of these issues may help target finite resources to aid their management.

The utility of performance status as a decision-making and prognostic aid is already integrated into oncological care. The current study suggests that this clinical indicator could also be utilised to aid timely, proactive supportive care interventions. Further work is needed to evaluate how this could be integrated into lung cancer care and which health professions could best provide the interventions required

Finally, the utility of the Palliative Outcome Scale in lung cancer care could be further evaluated and compared to other validated tools. This study could be developed to assess which tools can be used in combination and continue to retain clinical relevance.

12.9 Conclusions and Recommendations

In meeting the aims of this service evaluation, a high supportive care needs prevalence within lung cancer patients attending the Stobhill lung cancer clinic has been

demonstrated and recommendations regarding future service development have been made.

Increased anxiety has been identified as a key psychosocial issue, including personal anxiety and, particularly anxiety within the support network. The physical symptoms of pain and dyspnoea are particularly prevalent in this population.

In keeping with the importance of performance status in decision-making in lung cancer treatments, performance status has an important role in the targeting of referrals to supportive care services for individual assessment. However, supportive care needs are apparent at all stages of the lung cancer journey and are not predicted by histology, stage, gender or deprivation. Increased supportive care needs did not predict survival in multivariate analyses when controlled for performance status and other factors.

Lung cancer remains the leading cause of cancer-related death in Scotland. Over 4000 patients are diagnosed each year and, despite some treatment advances, overall survival remains poor. The psychosocial and physical symptom burden of lung cancer patients is greater than many other cancers and conditions. Systematic review of symptoms, psychosocial issues, spiritual needs and carers' needs remains vital to identifying those individuals who would most benefit from focused care.

Specific attention to supportive care in future service planning, service delivery, research and investment is required for people who will be diagnosed with lung cancer in Glasgow and elsewhere in the coming years.

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14 Appendices

Appendix 1: Local Research Ethics Committee Review

Full title of study: **The clinical care and follow-up of lung cancer patients in a hospital setting**

REC reference number: **07/S0704/65**

Thank you for seeking the Committee's advice about the above project. Thank you also to Dr Buchanan for taking the time to attend the meeting held on 7th September 2007.

You provided the following documents for consideration which were considered by the Committee:

Document	*Version*	*Date*
Application		07 September 2007
Investigator CV		08 August 2007
Protocol		
Covering Letter		08 August 2007
Questionnaire: Palliative Outcome Scale	2	
Questionnaire: Lung Multidisciplinary Clinic 2007	1	25 July 2007
Questionnaire: Lung Multidisciplinary Clinic 2006	1	25 July 2007
CV for Alan Thompson		26 July 2007

The Research Governance Framework (RGF) sets out the responsibilities and standards that apply to work managed within the formal research context.

The REC had a lengthy discussion as to whether this study is Service Evaluation or Research. The main points addressed centred on the generation of new knowledge, a potential change in practice and the fact that the study had been re-badged as research to accommodate the higher degree proposal. It was noted that service evaluation or audit can lead to changes in clinical practice and that on balance, the entire study could be seen as an audit of multi-disciplinary lung cancer management at Stobhill, measured against known standards of care in published literature.

The project is therefore considered to be audit/service evaluation and should not be managed as research. Therefore it does not require ethical review by a NHS Research Ethics Committee or approval from the NHS R&D office.

However, if you feel that ethical review by a NHS REC is essential, please write setting out your reasons and the Chair will be pleased to consider further.

You must check with the clinical governance office what other review arrangements or sources of advice apply to projects of this type. You should ensure that the project is not presented as research in the NHS organisation.

This letter should not be interpreted as giving a form of ethical approval to the project, but it may be provided to a journal or other body as evidence that ethical approval is not required under NHS research governance arrangements.

07/S0704/65	**Please quote this number on all correspondence**

Yours sincerely

S Macgregor

Mrs Sharon Macgregor
Administrator

Appendix 2: Confirmation letter of POS Registration

School of Medicine
at Guy's, King's College and St Thomas' Hospitals

Department of Palliative Care, Policy & Rehabilitation

Professor Irene Higginson
BMedSci BMBS FFPHM PhD FRCP
Head of Department:
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KING'S College LONDON

18th August 2010

Dr Deans Buchanan
13 Evelyn Terrace
Perth
PH2 OBS

Dear Dr Buchanan

I can confirm that you completed the POS online registration on the 25th January 2006 and the POS User's Guide was posted to you on the 17th February 2006.

Yours sincerely

Leonie Hayes
Academic Administrator

Appendix 3: The Lung Multidisciplinary Clinic Questionnaire

Please answer the following questions by ticking the box next to the answer that is most true for you. Your answers will help us to keep improving your care and will be analysed to further develop service and help in the care of others. If possible, please complete one each clinic visit. Thank you.

Name: _____ Date of Birth: _____ Weight: ____

Date: _____ Age: _____

1. How long ago was your last clinic review?
   - ❑ This is my first appointment
   - ❑ Less than 4 weeks
   - ❑ 4 - 8 weeks
   - ❑ 2-4 months
   - ❑ Greater than 4 months

2. Have you experienced any new or worsening symptoms since last being at clinic?
   - ❑ No
   - ❑ Yes

3. If any, what have been your main problems in the last 4 weeks?

   a)_____

   b)_____

4. Have you had to contact your GP in the last 4 weeks? If so Why?
   - ❑ No
   - ❑ Yes Why? _____

5. Over the past 4 weeks, have you been affected by pain?
   - ❑ Not at all, no effect
   - ❑ Slightly – but not bothered to be rid of it
   - ❑ Moderately – pain limits some activity
   - ❑ Severely – activities or concentration markedly affected
   - ❑ Overwhelmingly – unable to think of anything else

6. Over the past 4 weeks, have you been affected by shortness of breath?
   - ❑ Not at all, no effect
   - ❑ Slightly – but not bothered to be rid of it
   - ❑ Moderately – breathlessness limits some activity
   - ❑ Severely – activities or concentration markedly affected
   - ❑ Overwhelmingly – unable to think of anything else

7. Over the past 4 weeks, have you been affected by cough?
   - ❑ Not at all, no effect
   - ❑ Slightly – but not bothered to be rid of it
   - ❑ Moderately – cough limits some activity
   - ❑ Severely – activities or concentration markedly affected
   - ❑ Overwhelmingly – unable to think of anything else

8. Over the past 4 weeks, have you been affected by coughing up blood?

- ❑ Not at all, no effect
- ❑ Slightly – but not bothered to be rid of it
- ❑ Moderately –happens quite often
- ❑ Severely – happens a lot
- ❑ Overwhelmingly – unable to think of anything else

9. Over the past 4 weeks, have any other symptoms e.g. Nausea or constipation been affecting how you feel? *(If Yes then please write symptoms)*

- ❑ No, not at all
- ❑ Slightly
- ❑ Moderately
- ❑ Severely
- ❑ Overwhelmingly

What Symptom(s)? _____

10. **6 months ago -** How would you describe your ability to be active?

- ❑ Fully active, no difference from my normal
- ❑ Restricted in strenuous activity, can manage most other things with ease
- ❑ Up and about for the majority of the day, can care for myself but cannot carry out normal activities (e.g. Shopping or cleaning by myself)
- ❑ Can only do some things for myself, have to rest for more than half the day
- ❑ I do not get out of bed or my chair and I need help with everything

11. **Over the past 4 weeks -** how would you describe your ability to be active?

- ❑ Fully active, no difference from my normal
- ❑ Restricted in strenuous activity, can manage most other things with ease
- ❑ Up and about for the majority of the day, can care for myself but cannot carry out normal activities (e.g. Shopping or cleaning by myself)
- ❑ Can only do some things for myself, have to rest for more than half the day
- ❑ I do not get out of bed or my chair and I need help with everything

12. Over the past 4 weeks, have you been feeling anxious or worried about your illness or treatment?

- ❑ No, not at all
- ❑ Occasionally
- ❑ Sometimes – affects my concentration now and then
- ❑ Most of the time – often affects my concentration
- ❑ Can't think of anything else – completely pre-occupied by worry and anxiety

13. Over the past 4 weeks, have any of your family or friends been anxious or worried about you?

- ❑ No, not at all
- ❑ Occasionally
- ❑ Sometimes – it seems to affect their concentration
- ❑ Most of the time
- ❑ Yes, always pre-occupied with worry about me

14. Over the past 4 weeks, have you been able to share how you are feeling with your family or friends?

    - ❑ Yes, as much as I wanted to
    - ❑ Most of the time
    - ❑ Sometimes
    - ❑ Occasionally
    - ❑ Not at all with anyone

15. Over the past 4 weeks, have you felt life was worthwhile?

    - ❑ Yes, all the time
    - ❑ Most of the time
    - ❑ Sometimes
    - ❑ Occasionally
    - ❑ Not at all

16. Over the past 4 weeks, have you felt good about yourself?

    - ❑ Yes, all the time
    - ❑ Most of the time
    - ❑ Sometimes
    - ❑ Occasionally
    - ❑ No, not at all

17. Over the past 4 weeks, how much information have you and your family or friends been given?

    - ❑ Full information or as much as wanted – always feel free to ask
    - ❑ Information given but hard to understand
    - ❑ Information given on request but would have liked more
    - ❑ Very little given and some questions were avoided
    - ❑ None at all – when we wanted information

18. Over the last 4 weeks, have any practical matters resulting from your illness, either financial or personal, been addressed?

    - ❑ I have had no practical problems
    - ❑ Practical problems have been addressed and my affairs are as up to date as I would wish
    - ❑ Practical problems are in the process of being addressed
    - ❑ Practical problems exist which were not addressed

19. Over the past 4 weeks, how much time do you feel has been wasted on appointments relating to your healthcare, e.g. Waiting round for transport or repeating tests?

    - ❑ None at all
    - ❑ Up to half a day wasted
    - ❑ More than half a day wasted

20. Do you feel you are seeing too many different Health care Professionals?
    - ❑ No
    - ❑ Yes

21. How satisfied were you with the way tests were carried out
    (Taking into account time taken, discomfort and side effects)

    - ❑ Very Satisfied
    - ❑ Satisfied
    - ❑ Unsatisfied
    - ❑ Very Unsatisfied Main reason : _____

22. How satisfied were you with the way in which you were told what was wrong?

    - ❑ Very Satisfied
    - ❑ Satisfied
    - ❑ Unsatisfied
    - ❑ Very Unsatisfied Main reason : _____

23. How satisfied are you with the way in which you are being followed up at the hospital clinic?

    - ❑ Very Satisfied
    - ❑ Satisfied
    - ❑ Unsatisfied
    - ❑ Very Unsatisfied Main reason : _____

24. How would prefer your on-going follow up to be organised?

    - ❑ Regular, routine appointments at this clinic even if you have no new or changing symptoms
    - ❑ If new or changing symptoms develop then an arranged, rapid return to this clinic through your own GP
    - ❑ By a hospital-based specialist nurse-led service with return to this clinic only if there were new issues to be assessed

25. Who do you think is the main person in overall charge of your care?
    (Please pick one main person)

    - ❑ General Practitioner
    - ❑ Respiratory Consultant
    - ❑ Oncologist
    - ❑ Surgeon
    - ❑ Palliative Care Consultant
    - ❑ Specialist Nurse
    - ❑ Uncertain
    - ❑ Other _____

26. How did you complete this questionnaire?

    - ❑ On my own
    - ❑ With the help of a friend or relative
    - ❑ With help from a member of staff

Appendix 4: The Palliative Outcome Scale, Version 1

Palliative care Outcome Scale
PATIENT QUESTIONNAIRE

Patient name: ..... Assessment date: .....

Date of birth: ..... Assessment no: .....

Care setting: .....

Please answer the following questions by ticking the box next to the answer that is most true for you. Your answers will help us to keep improving your care and the care of others. Thank you.

1 **Over the past 3 days, have you been affected by pain?**

- ❑ 0 Not at all, no effect
- ❑ 1 Slightly – but not bothered to be rid of it
- ❑ 2 Moderately – pain limits some activity
- ❑ 3 Severely – activities or concentration markedly affected
- ❑ 4 Overwhelmingly – unable to think of anything else

2 **Over the past 3 days, have other symptoms e.g. nausea, coughing or constipation been affecting how you feel?**

- ❑ 0 No, not at all
- ❑ 1 Slightly
- ❑ 2 Moderately
- ❑ 3 Severely
- ❑ 4 Overwhelmingly

3 **Over the past 3 days, have you been feeling anxious or worried about your illness or treatment?**

- ❑ 0 No, not at all
- ❑ 1 Occasionally
- ❑ 2 Sometimes – affects my concentration now and then
- ❑ 3 Most of the time – often affects my concentration
- ❑ 4 Can't think of anything else - completely pre-occupied by worry and anxiety

4 **Over the past 3 days, have any of your family or friends been anxious or worried about you?**

- ❑ 0 No, not at all
- ❑ 1 Occasionally
- ❑ 2 Sometimes – it seems to affect their concentration
- ❑ 3 Most of the time
- ❑ 4 Yes, always preoccupied with worry about me

5 **Over the past 3 days, how much information have you and your family or friends been given?**

- ❑ 0 Full information or as much as wanted – always feel free to ask
- ❑ 1 Information given but hard to understand
- ❑ 2 Information given on request but would have liked more
- ❑ 3 Very little given and some questions were avoided
- ❑ 4 None at all – when we wanted information

6 **Over the past 3 days, have you been able to share how you are feeling with your family or friends?**

- ❑ 0 Yes, as much as I wanted to
- ❑ 1 Most of the time
- ❑ 2 Sometimes
- ❑ 3 Occasionally
- ❑ 4 Not at all with anyone

7 **Over the past 3 days, have you felt that life was worthwhile?**

- ❑ 0 Yes, all the time
- ❑ 1 Most of the time
- ❑ 2 Sometimes
- ❑ 3 Occasionally
- ❑ 4 No, not at all

8 **Over the past 3 days, have you felt good about yourself as a person?**

- ❑ 0 Yes, all the time
- ❑ 1 Most of the time
- ❑ 2 Sometimes
- ❑ 3 Occasionally
- ❑ 4 No, not at all

9 **Over the past 3 days, how much time do you feel has been wasted on appointments relating to your healthcare, e.g. waiting around for transport or repeating tests?**

- ❑ 0 None at all
- ❑ 2 Up to half a day wasted
- ❑ 4 More than half a day wasted

10 **Over the past 3 days, have any practical matters resulting from your illness, either financial or personal, been addressed?**

- ❑ 0 Practical problems have been addressed and my affairs are as up to date as I would wish
- ❑ 2 Practical problems are in the process of being addressed
- ❑ 4 Practical problems exist which were not addressed
- ❑ 0 I have had no practical problems

11 **If any, what have been your main problems in the last 3 days?**

1 .....

2 .....

12 **How did you complete this questionnaire?**

- ❑ 0 On my own
- ❑ 1 With the help of a friend or relative
- ❑ 2 With help from a member of staff

Appendix 5: POS Responses For All Q1

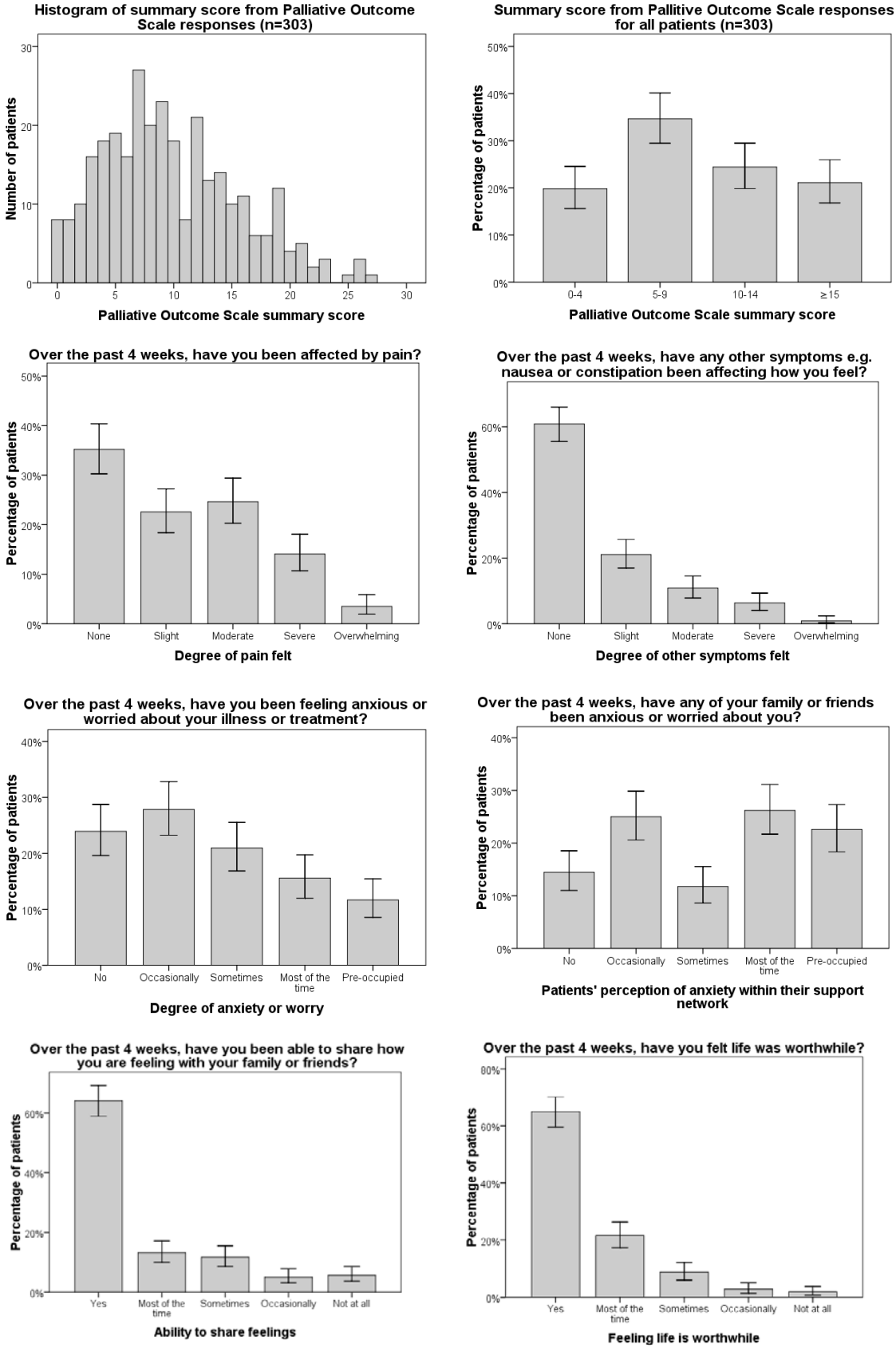

Figure 21A: Histogram and bar charts of patient responses to POS questions (Q1); 95% confidence intervals included.

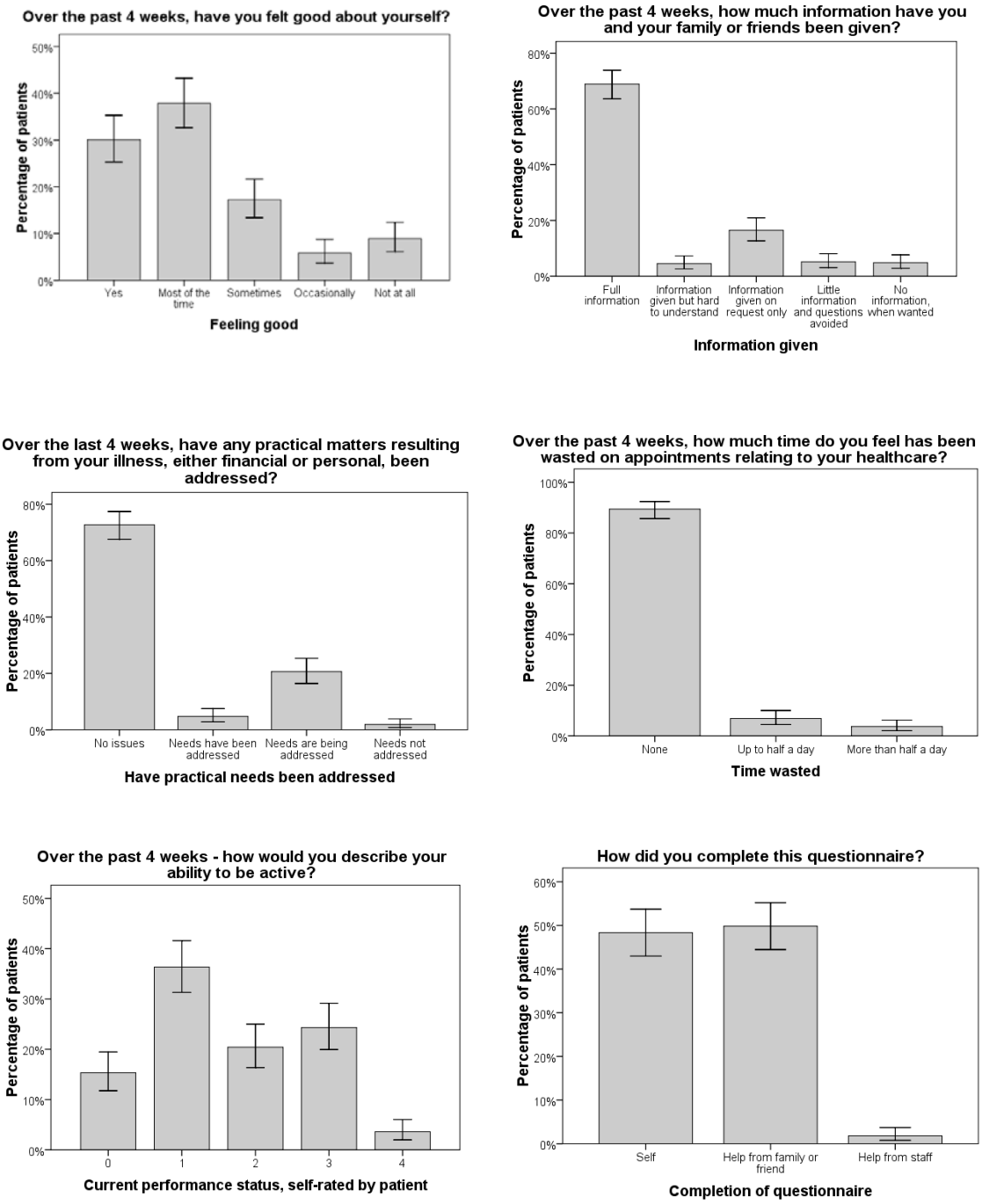

Figure 21B: Bar charts of patient responses to POS questions and self-rated performance status (Q1); 95% confidence intervals included.

Appendix 6: POS Responses for All Newly Diagnosed Patients

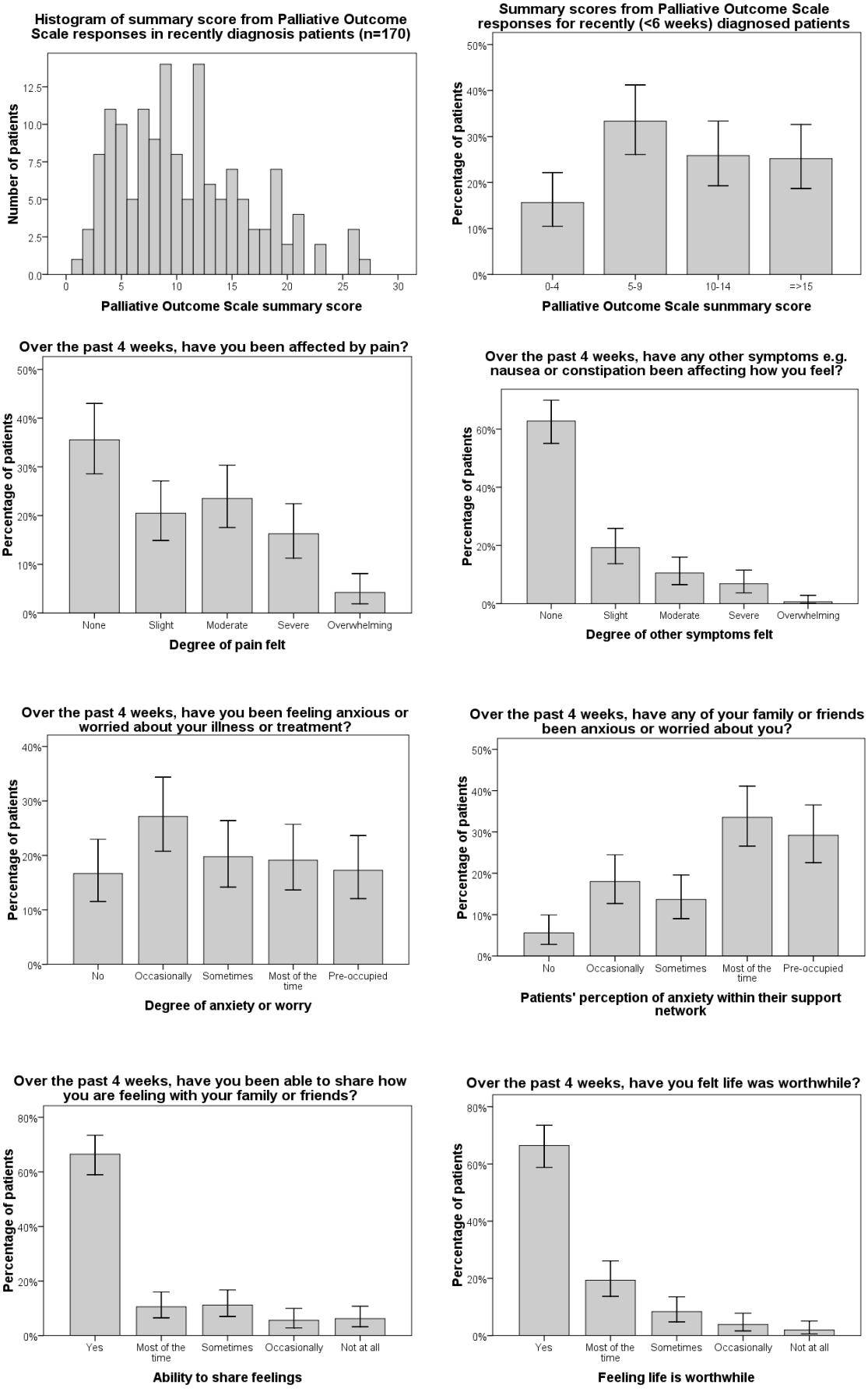

Figure 22A: Histogram and bar charts of recently diagnosed (<6 weeks) patients' responses to POS questions (Q1); 95% confidence intervals included.

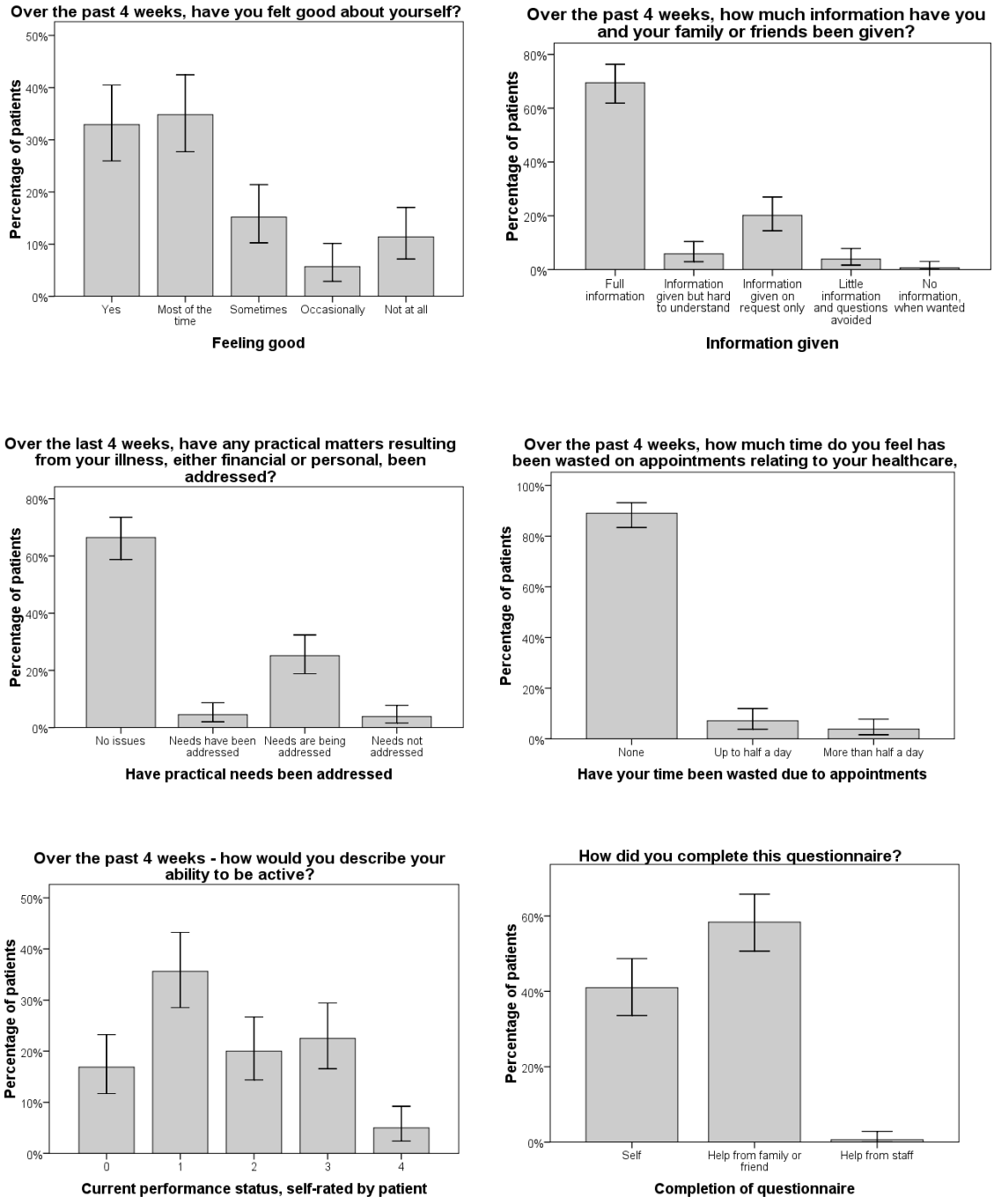

Figure 22B: Bar charts of recently diagnosed patients' responses to POS questions and self-rated performance status (Q1); 95% confidence intervals included.

Appendix 7: POS Responses for Patients Within Last Three Months

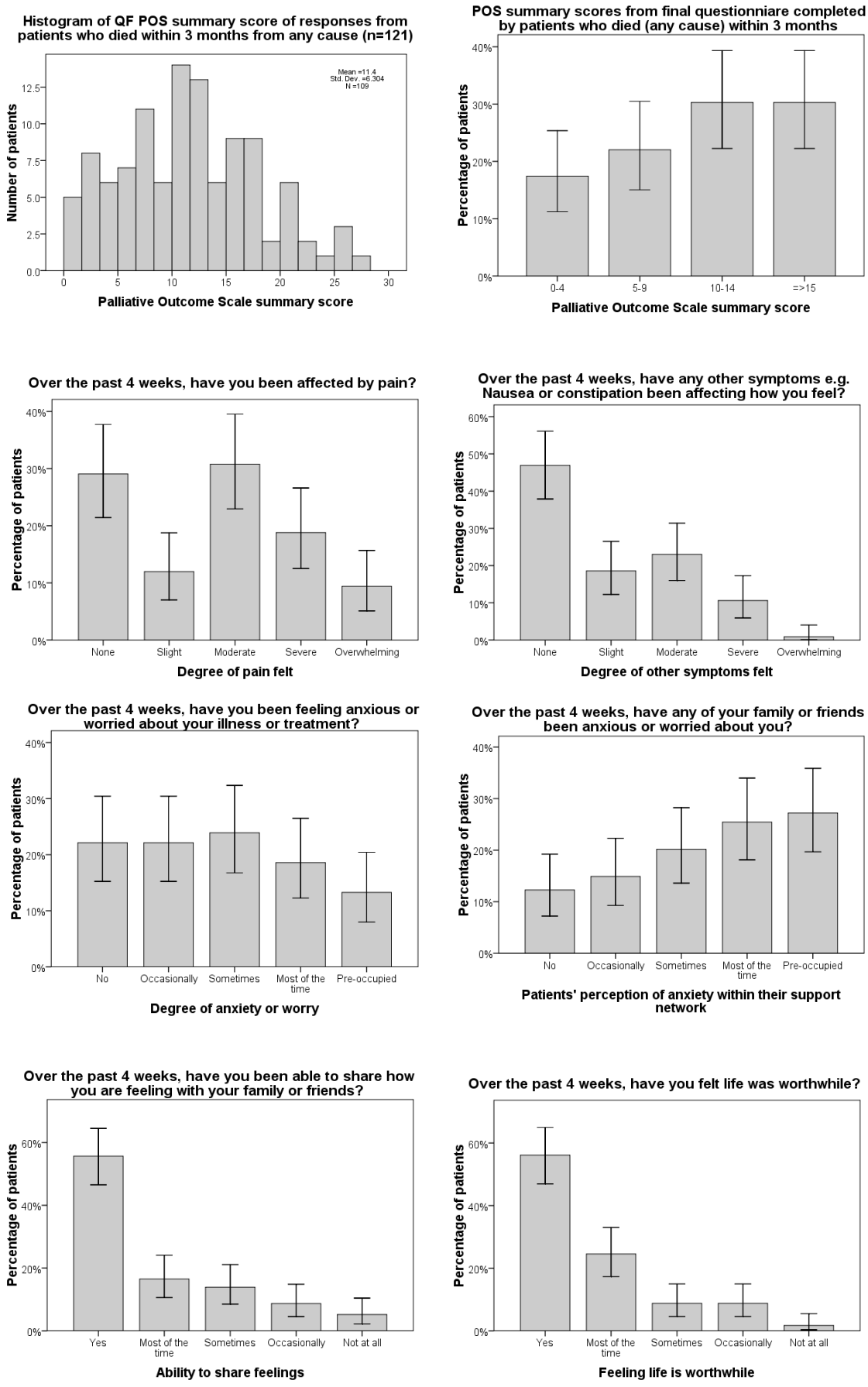

Figure 23A: Histogram and bar charts of patients' responses to POS questions (QF) within three months of death (from any cause); 95% confidence intervals included.

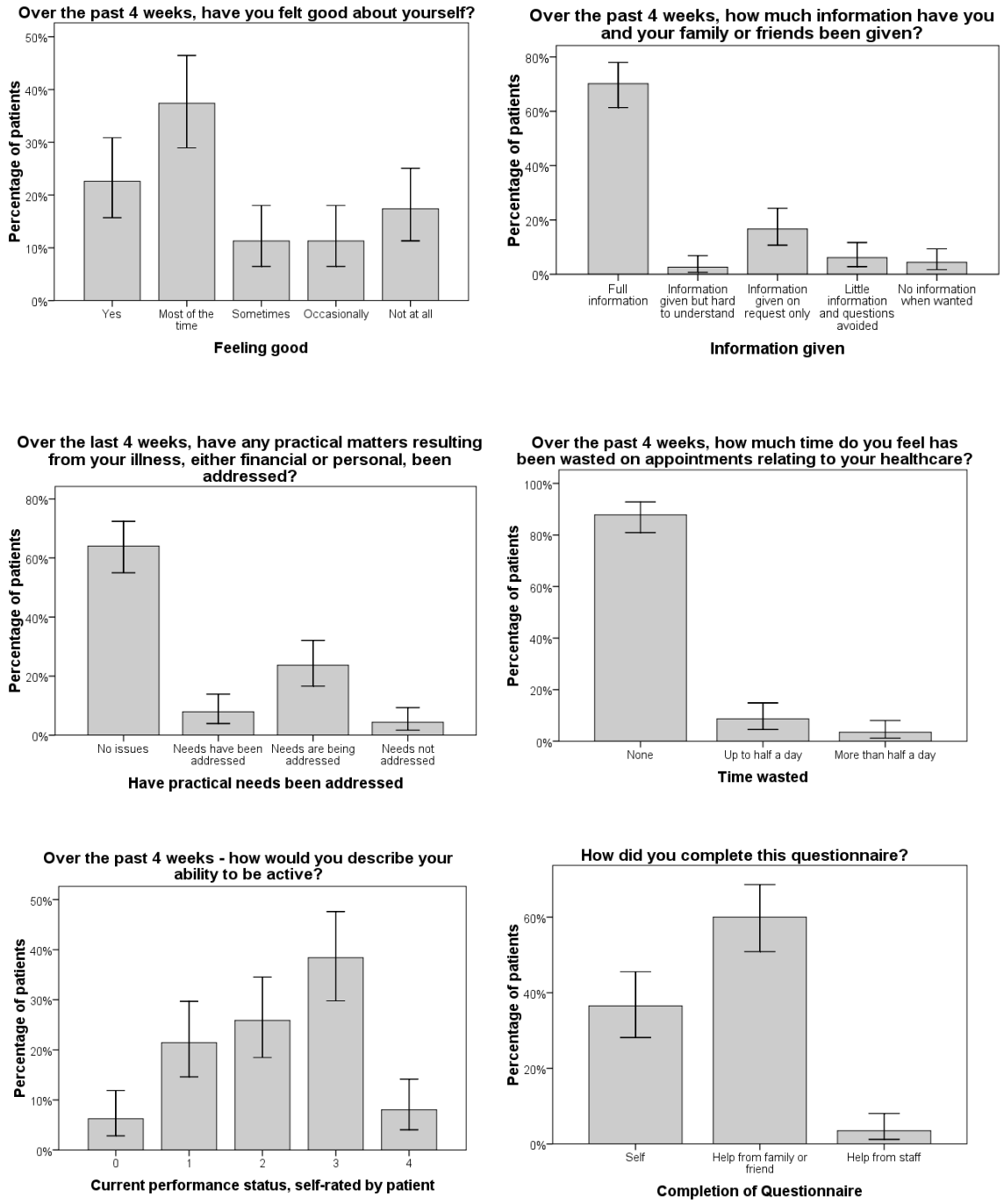

Figure 23B: Bar charts of patients' responses to POS questions (QF) and self-rated performance status within three months of death (any cause); 95% confidence intervals included.

Appendix 8: Outline of Statistical Tests

Student's t Test

When comparing two independent groups of data, it is important to know the distribution of the data. This will determine which tests are appropriate to use.

For normally (Gaussian) distributed data, any significant difference between the two groups can be assessed using Student's t test. This test calculates a t statistic based on standard deviations (using standard error, s.e.) and the difference between the means of the two groups compared to an expected difference if the null hypothesis is true. (This would be zero if no difference.)

$$t = \frac{\text{obs diff between sample means - exp diff between pop means}}{\text{estimate of s.e. of diff between sample means}}$$

This t statistic describes the probability of that difference occurring by chance (the probability, or p value, can be obtained from published tables or by computation through, for example, SPSS). By convention, if the probability is less than 5% ($p<0.05$), this is considered a significant result and the null hypothesis (that there is no difference between the groups) can be rejected.

Mann Whitney U Test

When data is not normally distributed (non-parametric), then the t test cannot be used. To compare groups of non-parametric data, the Mann Whitney U test can be used. This is based on ranking the data. As such, large scores are represented by high ranks and low scores are represented by lower ranks. The analysis is then carried out on the ranks. If the null hypothesis is true (that there is no difference between the two groups) then there is also no difference in the ranking of the two groups. If there is a difference, then this should be represented in a difference of ranking and in the sum of the ranks. Repeating numbers (that would be normally ranked the same) are assigned increasing ranks for each occurrence and then averaged to produce a single rank for all occurrences (e.g. three occurrences of the value 6 could be ranked 3,4 and 5 but would be assigned the average rank of 4). The test statistic (U) is calculated from the sample sizes and the summed rank of group 1:

$$U = n_1 n_2 + \frac{n_1(n_1+1)}{2} - R_1$$

n_1 and n_2 are sample sizes for group 1 and 2, respectively

R_1 is sum of ranks for group 1

The significance ($p<0.05$) of the difference can be evaluated by calculating a z score from the test statistic (lowest sum of ranks), the mean of test statistic (calculated knowing group sizes) and the standard error of the test statistic.

$$z = \frac{\text{test statistic - mean of test statistic}}{\text{s. e. of test statistic}}$$

The significance of the z score can be obtained from published tables or computed by the statistics programme.

The Wilcoxon rank-sum test can also be used to compare ranked non-parametric data. In this case the test statistic is the value obtained for the group with the lowest sum of ranks. This method is closely related to the Mann-Whitney U test and gives similar results through similar methods.

Chi Squared Testing

Chi squared (X^2) testing compares categorical data in one (or more) group and another. The observed data can be compared to expected data determining if the null hypothesis (that there is no difference) can be rejected or accepted. Expected frequencies for each cell are calculated by assuming the null hypothesis that the proportions of the numbers in each cell are the same and constructing a contingency table to that effect.

$$E = \frac{\text{row total} * \text{column total}}{\text{n}}$$

E= expected frequency and n= total number of observations

From these observed and expected frequencies, the X^2 statistic can be calculated.

$$X^2 = \sum \frac{(O * E)^2}{E}$$

The probability of attaining this value can then be looked up from the appropriate X^2 distribution table.

Fisher's Exact Testing

Comparison of a 2x2 table can be limited if the frequencies are too small for the X^2 test. The sampling distribution of the X^2 statistic has an appropriate X^2 distribution. The larger the sample, the closer the approximation; the smaller the sample, the less good the approximation.

The exact probability test devised by Fisher, Irwin and Yates allows this situation to be resolved. The method describes the probability of observing a set of frequencies if the totals of both rows and columns in a 2x2 table are kept at their observed values. The probability of gaining a more extreme set of data (i.e. greater disparity in frequencies between the two groups) is then considered. This is akin to examining the tails of the distribution of continuous data. The 2x2 contingency tables are rearranged in each possible sequence that maintains the same row and column totals. The exact probability for each of these tables can be calculated. The addition of probabilities from these tables allows the overall probability for each array plus any more extreme array to be calculated.

Correlation

When evaluating whether two variables are associated, the simplest approach is to consider their covariance. Variance of a single variable is the average amount that the data vary from the mean.

$$\text{Variance} = \frac{\sum (x_i - \bar{x})^2}{N-1}$$

(note: the standard deviation is the square root of the variance)

If we consider two variables, we are interested in what happens to the one variable when the other one deviates from the mean. By multiplying the standard deviations of two variables, we get the cross-product of the deviations. The covariance can be calculated from a similar formula to that for the variance above.

$$\text{Covariance} = \frac{\sum (x_i - \bar{x})(y_i - \bar{y})}{N - 1}$$

As measures can be in different units, this is standardised using the standard deviations to give an *r* value which is the correlation coefficient.

$$r = \frac{\text{covariance of xy}}{\text{product of xy standard deviations}}$$

Regression

Regression techniques allow the relationship between two or more variables to be further examined than only correlation or association. Regression evaluates how well one variable (outcome) is predicted by another variable (predictor) and allows construction of a model of prediction. Such models can be conceptually considered as:

Outcome = model + error

Linear regression assumes a linear relationship between the variables and as such can be described using the equation of a line:

$$y = b_0 + b_1 x$$

y = outcome, b_0 = y intercept, b_1= gradient and x=predictor

The data is fitted with a **line of best fit** which is the line that minimises the vertical distance (**the residual**) from actual data point to fitted line the most for all points. As points will occur above and below the line (and summation of the positive and negative residuals would effectively cancel each other out), the **sum of the squared residuals** is used. This is the **line of least squares**. The equation of the line can be used to described the line and as the model of prediction. Not all lines will describe the data well as the error is too great. A regression line (or model) can be assessed for **goodness of fit**. This is done by comparing the best model to the most basic model. This basic model can be based on the mean and the **sum of squares** of differences around the mean. The improvement of the ability to predict by the model is calculated by the difference between the sum of squared residuals and the sum of squares around the mean. The difference is called the **model sum of squares** (SS_m); if it is large, there is a big difference using the model compared to using the means. The exact proportional improvement from using means can be calculated by dividing SS_m by the SS of the

mean. The resulting value is the **R^2 value** which can be multiplied by 100 to give the percentage of variance that the model explains.

R^2 in regression is the same as the R^2 obtained in correlation.

Odds ratios

The odds ratio is a ratio of the odds of an event in one group divided by the odds of that event in another group. The odds of an event is the ratio of the number of that event to the number of non-events (e.g. the odds of throwing a six with a standard die is 1:5 or 0.2). An odds ratio of 1 means there is no change in odds as the predictor increases (or occurs); an odds ratio of less than one means as the predictor increases (or occurs) the odds of the outcome occurring decreases; for an odds ratio greater than one, the odds of the outcome occurring increases as the predictor increases (or occurs).

Logistic Regression

Linear regression is only suitable for continuous outcome variables and cannot be used to consider a dichotomous outcome (binary outcome), such as vital status. Logistic regression allows the relationship between multiple predictor variables and a dichotomous outcome variable to be examined. Therefore, logistic regression models allow the investigator to predict which of the two outcome categories each case is likely to belong to given certain other information. The impact of predictor variables is usually described in terms of the odds ratio.

Logistic regression does not assume a linear relationship between outcome and predictor variables, and predictor variables can be categorical or continuous. It is non-parametric but does require data to be independent and predictors should not be too highly correlated with each other. The outcome categories must be mutually exclusive.

The significance of each variable within the model can be assessed through the Wald Statistic. This has a X^2 distribution and is used to determine if the regression coefficient is significantly different from 0. Hosmer and Lemeshow's statistic is utilised to evaluate that the overall model is significant. This is a ratio of what variance the new model can explain compared to the variance the baseline model explained. Hosmer and Lemeshow's goodness of fit statistic is derived from an ordered grouping of the

observed outcomes and the predicted outcomes. The resulting test statistic has a X^2 distribution and a significance level can be derived. If the value is greater than 0.05 then we fail to reject the null hypothesis that there is no difference between observed and predicted values (i.e. the model predictions fit the data well).

The additional technique of stepwise modelling can be used to identify the most significant factors in a predictive model. Backwards logistic regression is usually preferred for exploratory analysis to identify factors of significance when there is no clear theoretical understanding of important predictors. This involves entering all the predictors in the model and removing non-significant factors until the model is refined. By starting with all the predictors in the model this reduces the occurrence of suppressor effects (i.e. when a variable is significant only when another variable is held constant). Conversely, forwards logistic regression can be used when there is a strong theoretical basis for including certain predictors, but it is more open to suppressor effects.

Kaplan-Meier

Regression analysis describes the relationship between an outcome measure and one or more predictors. Survival analysis evaluates such a relationship and models the time it takes for events to occur. Kaplan-Meier cumulative survival curves can be used to model univariate survival (i.e. the probability of survival at any given time from a given point). Such survival curves can also be compared for survival differences across grouped survival (e.g. survival from diagnosis in males and female).

In Kaplan-Meier analysis, the proportion of survivors from a given point and over a specified period of time can be calculated for a population. This estimate of the proportion surviving is also an estimated probability of survival to that time for a member of the population from which the sample has been drawn. Because the event may not have occurred for all patients within the study time, censoring is used. Over each survival time considered, the probability of survival is calculated by the product of those surviving at the beginning of the period examined and those surviving at the end of that period. For example, if 32 patients of 38 were alive at the end of one month (proportion alive = 0.842), and 27 of that 32 (proportion alive = 0.844) were still alive at the end of the second month, the probability of survival at two months is 0.842 x 0.844 = 0.711. This can be repeated until the last event. Observations censored at any time will affect the number of patients included in the baseline survival proportion. These

survival probabilities can be graphed as 'curves' in which each step down occurs with an observed event. Censored events are also plotted on the curve. This is called the Kaplan-Meier curve.

Comparison of two or more survival curves can be carried out using the log rank test. This tests the null hypothesis that there is no difference between the population survival curves (i.e. the probability of an event occurring at any given time is the same for both populations). The test statistic is calculated by:

$$X^2(\text{log rank}) = \frac{(O_1 - E_1)^2}{E_1} + \frac{(O_2 - E_2)^2}{E_2}$$

O is the observed events and E is the expected number of events

The expected number of events for a group is the sum of expected events for that group at each time interval. The expected number of events for each interval is calculated as the risk of that event (number of events/number of people in group) multiplied by the number in the group at the time concerned. The test statistic can be compared with a X^2 distribution with df=1 for significance. Where p is <0.05, there is a significant difference and the null hypothesis is rejected. The log rank test does not take any other variables into account.

Cox's Proportional Hazards Model (Cox Regression)

Cox regression allows event-time analysis to consider multiple variables. One or more predictor variables (covariates) are used to predict a status variable (an event, usually death) over time. First described by D.R. Cox in 1972, this form of survival analysis is now used widely. Cox regression differs from logistic regression in that it describes the hazard ratio (*rate* of incidence of hazardous event) instead of the odds ratio (ratio of proportions of those who have experienced the hazardous event). In this regard, Cox regression is analogous to a multiple linear regression model except that the outcome variable is a hazard rate rather than a hazard state.

Cox regression is regarded as semi-parametric and does not make assumptions about the distribution of the data or the probability distribution of the hazard (usually dying), and it can accommodate both discrete and continuous measures of event times. However, it is assumed in Cox regression that the risk of dying in one group at one time will be the

same at any other time, and that the effects of different variables on survival are constant over time.

Stepwise procedure can be used to evaluate which predictor variables are significant contributors to the model. Both forwards and backwards stepwise methods can be utilised, but backwards modelling is preferred when there is no clear theoretical framework for variable selection (i.e. the work is exploratory).

Appendix 9: Publications

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Perceptions of anxiety in lung cancer patients and their support network

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Abstract
Introduction Lung cancer is a disease of high symptom burden, major psychosocial impact and poor prognosis. Although diagnosis is individual, each patient operates within a social context. Patient perception of family's or friends' concern may affirm the presence of support or may drive personal anxiety. Perceived worry may impact on freedom to discuss illness or symptoms within the support network. The validated palliative outcome scale quantifies physical and psychosocial needs. It also evaluates anxiety felt and anxiety perceived in the support network. This study examined lung cancer patients' symptoms, performance status, their supportive care needs and their perception of family's/friends' anxiety.
Goals of work The aim of this study was to evaluate lung cancer patients' anxiety, physical symptoms, performance status and their perception of anxiety within their support network.
Patients and methods The study was a prospective observational evaluation of 170 lung cancer out-patients using an adapted palliative outcome scale questionnaire. Comparison was made between patients perceiving high anxiety within their support network and those who perceiving low anxiety.
Main results Perceived familial and self-rated personal anxiety both increased as function declined ($p<0.001$; $p=0.001$). Increased perceived worry was associated with increased physical symptoms [dyspnoea ($p<0.001$), cough ($p=0.001$), haemoptysis ($p=0.009$)], low self-esteem ($p=0.004$) and feeling lack of worth ($p=0.035$). Perception of increased worry did not influence whether patients felt able to share their feelings ($p=0.362$).
Conclusions As physical function declines and symptoms increase, patients are more worried themselves and perceive increased anxiety within their support network. However, this circle of anxiety did not impair the perception that feelings could be shared within the support network.

Keywords Anxiety · Support network · Lung cancer · Supportive care

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Introduction

Lung cancer is the commonest cause of cancer-related deaths worldwide. In Britain, it accounts for 25% of all cancer deaths [36]. The prognosis remains poor with an overall 5-year survival of around 7% [6, 15, 35]. Symptom distress is higher than other cancers and there is a large unmet psychosocial burden [7, 11, 20, 25, 30]. Anxiety and worry within the lung cancer population are both common and underestimated, and they impact significantly on quality of life [1, 5, 7, 14, 27, 29, 32].

The impact of anxiety and worry on day-to-day life is reflected in the etymology of both words. Anxiety derives from the Latin 'anxius' meaning 'to choke'. Worry originates from the Anglo-Saxon 'wyrgan' meaning 'to strangle' [10]. Manifestations of anxiety can be classed as physical (including sweats, palpitation, gastrointestinal disturbance, panic attacks and dyspnoea), behavioural (unease, restlessness and reassurance seeking) and psycho-emotional (apprehension, recurrent and intrusive thoughts and loss of concentration) [3, 39, 42]. A spectrum of anxiety is observed within both the general and cancer populations. This includes adaptive anxiety, maladaptive anxiety and classifiable anxiety disorders (such as phobias, panic attacks, generalised anxiety disorders and post-traumatic distress) [24, 41, 46]. Maladaptive anxiety is out of proportion to the stimulus, persists and disrupts function and quality of life [41].

Anxiety in cancer

Cancer is a threatening diagnosis. The word 'cancer' has been used in studies to provoke anxiety [42]. Within the cancer population, there is a higher prevalence of anxiety and mixed anxiety–depression than the general population [39]. It can be difficult to assess for anxiety in cancer as the changing illness trajectory, effect and side effects of treatment, and the persistent threat of the diagnosis and associated prognostic uncertainty, lead to a dynamic situation [42]. However, anxiety can become a significant identifiable problem requiring specific assessment and management. Once identified, management of anxiety in cancer includes good communication, information giving, psychological support and pharmacological interventions [3, 39, 42].

Anxiety in lung cancer

Physical decline in advanced cancer and lung cancer has been well characterised [33]. Lung cancer is often an acute illness with rapid physical decline, high symptom burden and short prognosis [11, 25]. Anxiety and distress are not predictable by gender, age or stage of lung cancer but may peak at certain stages of disease—diagnosis, identification of disease progression and the beginning of the terminal phase [33]. There is some evidence that anxiety in cancer is associated with poor performance status (PS) and high symptom burden [40]. As such, lung cancer patients are likely to be at risk of anxiety. The small body of research into this area provides some consistent evidence that psychosocial distress is high in the lung cancer population [12, 13, 29, 44].

Support network anxiety

Individual patients cope with illness and symptoms within the context of relationships with significant others [31, 38]. It has been suggested that sharing feelings with trusted and supportive people can improve emotional and cognitive processing of illness [21]. Lack of positive support may adversely affect this process. In tobacco-related disease, there may be additional elements with guilt or blame related to cigarette smoking. This may also affect the ability to discuss issues within the support network [21].

The concept of distinguishing symptom distress from symptom occurrence is gaining ground [4, 9, 45]. Assessment of symptom occurrence and symptom distress may differ between individuals, caregivers and significant others [4, 44, 45, 47]. Lack of concordance in distress recognition and identification of its cause, between patients and others, may influence the patients' perceptions of support.

Patient perception of family's or friends' worry may affirm presence of support or may drive personal anxiety. Perceiving high anxiety within your support network may impact on freedom to discuss illness or symptoms within the support network. Conversely, if this perceived anxiety is recognised as appropriate and reflective of care, then it may affirm feelings of support and facilitate shared feelings.

Objectives

This paper examines lung cancer patients' anxiety, physical symptoms, PS and their perception of anxiety within their support network. It utilises the validated Palliative Outcome Scale (POS) [16].

Materials and methods

POS quantifies physical and psychosocial needs in terms of impact on life. It quantifies patients' perceptions about worry within their support network and freedom to share feelings with others [16, 17, 19]. Individual questions and the summary score of POS have been shown to be valid (content, consensus, face and construct validity) and reliable (internal consistency and test/re-test reliability) in a multicentre study encompassing inpatient, outpatient and community care settings [16]. POS has been adapted for local needs in a variety of settings and in this study was applied in the ambulatory out-patient setting [16, 17, 23, 43]. POS asks patients to rate how different supportive care issues have affected them over the previous 3 days. This includes pain, 'other symptoms', their own anxiety, their perception of their support network's anxiety, mood and self-worth, health-care time use, practical problems and how much information has been given. In our questionnaire, the '3-day' period was adapted to suit out-patient review to consider 'the last 4 weeks'. Using the POS model of rating how affected the patient had been by symptoms as

'Not at all, no effect', 'Slightly—but not bothered to be rid of it', 'Moderately—symptom limits some activity', 'Severely—activities or concentration markedly affected' and 'Overwhelmingly—unable to think of anything else', three questions regarding dyspnoea, cough and haemoptysis were introduced. Finally, a question self-rating performance status was incorporated. This utilised the Eastern Co-operative Oncology Group (ECOG) performance status scale. ECOG quantifies function in patients from normal activity (0); restricted in strenuous activity (1); self-caring, ambulatory more than 50% of the day but unable to carry out work activities (2); limited self-care and ambulatory less than 50% of the day (3); unable to self-care and non-ambulatory (4); and dead (5) [34]. Each patient self-assessed their own current function from 0 to 4.

Patients with lung cancer were identified by clinic staff and asked to complete the questionnaire. The questionnaire was sequentially offered to all patients with lung cancer and was used within the clinical review to identify on-going problems. No other exclusions were applied. Over the course of 1 year, questionnaires including an adapted POS and respiratory symptom (dyspnoea, cough and haemoptysis) score were completed by 170 patients (new and returning) attending a lung cancer clinic. This represented the majority of patients attending the clinic in which around 170 new referrals are seen each year. Questionnaires were collated and audited alongside further data points derived from case notes.

The study was reviewed by the Local Research Ethics Committee. Information was entered into a spreadsheet and statistical analyses performed using SPSS™ Version 14.0. Descriptive statistics were generated on the sample characteristics. POS responses were compared between patients who felt lower anxiety and those who felt higher anxiety and patients who perceived high anxiety within their carers and those who perceived low anxiety (Mann–Whitney *U* test). The strength and direction of correlation between POS responses and 'anxiety felt' by the patient and also 'support network anxiety perceived' by the patient was further examined (Spearman's rho correlation coefficient).

Patients attending the out-patient lung cancer clinic at the study centre completed questionnaires over 12 months. This included new patients (66.5% patients within 28 days of diagnosis) and patients under long term follow-up (33.5% more than 28 days from diagnosis). Table one summarises the patient characteristics (Table 1).

Results

Anxiety and associations

Three main questions regarding anxiety and sharing of feelings are asked within POS:

Question 1: 'Over the past 4 weeks have you been feeling anxious or worried about your illness or treatment?'

Question 2: 'Over the past 4 weeks have any of your family or friends been anxious or worried about you?'

Question 3: 'Over the past 4 weeks have you been able to share how you are feeling with your family or friends?'

Each of these questions can be answered from 0 to 4, with 0 being no anxiety or feeling able to share, and 4 being preoccupation with worry or not being able to share with

Table 1 Characteristics of patients and gender differences (n=170)

	Males	Females	Total
All patients	78 (46%)	92 (54%)	170
Age (mean/range)	68 (45–85)	70 (53–90)	69 (45–90)
Performance status (median/range)	1.5 (0–4)	2 (0–4)	2 (0–4)
Diagnosis			
NSCLC	58 (34.1%)	57 (33.5%)	115 (67.6%)
Stage 1	14 (8.2%)	20 (11.8%)	34 (20.0%)
Stage 2	13 (7.6%)	6 (3.5%)	19 (11.2%)
Stage 3	15 (8.8%)	17 (10.0%)	32 (18.8%)
Stage 4	16 (9.4%)	14 (8.2%)	30 (17.6%)
SCLC			21 (12.4%)
Limited	4 (2.4%)	5 (2.9%)	9 (5.3%)
Extensive	4 (2.4%)	8 (4.7%)	12 (7.1%)
CLC	11 (6.5%)	20 (11.8%)	31 (18.2%)
Other (e.g. mesothelioma)	1 (0.6%)	2 (1.2%)	3 (1.8%)

PS performance status, *NSCLC* non-small cell lung cancer, *SCLC* small cell lung cancer, *CLC* clinicoradiological lung cancer

anyone. A small number of patients (less than 3%) did not answer all questions. Table 2 summarises the responses to these three questions.

Personal anxiety felt (mean 1.51, median 1, range 0–4, standard deviation (SD) 1.25) was reported to be 'low' (0–1) in 54.1% (n=92/170); 43.3% (n=74/170) described higher anxiety levels (2–4). Carer anxiety perceived in the support network (mean 2.12, median 3, range 0–4, SD 1.45) was reported to be 'low' (0–1) by 42.9% (n=73/170) of patients and described as 'higher' (2–4) by 54.1% (n=92/170). Being able to share feelings (mean 0.77, median 0, range 0–4, SD 1.22) was reported to be felt possible 'as much as I want' (0) or 'most of the time' (1) in 75% (n=129/170) of patients.

Associations of personal anxiety

Personal anxiety was categorised as 'lower' (0–1) and 'higher' (2–4). Differences between the lower and higher anxiety patients were examined in relation to the factors listed in Table 3. Statistical significance of any difference was assessed (Mann–Whitney U test). In addition, Spearman's rho correlation coefficient was utilised to define the direction and strength of correlation between 'anxiety felt' and the same factors (Table 3).

Significant differences were found between anxiety bands for physical symptoms [dyspnoea (p<0.001), cough (p=0.001), haemoptysis (p=0.015) and performance status (p<0.001)] and psychological symptoms [low self-esteem (p<0.001), feeling life was not worthwhile (p<0.001)]. These variables were significantly correlated to anxiety. Pain did not show a significant difference when examined across anxiety bands, but a positive and significant correlation was found. Survival from both diagnosis (p=0.24) and questionnaire date (p=0.050), were significantly different in each group of patients. Survival from diagnosis date and clinic date were both negatively correlated with increased anxiety.

Increased symptoms, decreased physical function, and shorter prognosis seem to be accompanied by increased anxiety—both felt by the patients and perceived by the patient to be present within the support network. There was no significant difference or correlation found in gender, age, histology, weight (diagnosis and current), diagnosis albumin, pain, 'other' symptoms and information needs. CRP was significantly higher in the higher band of anxiety patients

Patients' perception that they were able to share feelings within the support network correlated with anxiety levels but no significant difference between 'lower' and 'higher' anxiety was found (Mann–Whitney test). This is explained as the vast majority of patients (75%) felt able to share either 'as much as I want' or 'most of the time'.

Table 2 Responses to questions relating to anxiety and shared feelings

	No, not at all 0	Occasionally 1	Sometimes 2	Most of the time 3	Completely preoccupied 4	No answer	As much as I have wanted 0	Most of the time 1	Sometimes 2	Occasionally 3	Not with anyone 4	No Answer
Personal anxiety felt (Q1)	42 (24.7%)	50 (29.4%)	37 (21.7%)	22 (12.9%)	15 (8.8%)	4 (2.8%)						
Anxiety perceived in support network (Q2)	28 (16.5%)	45 (26.4%)	9 (5.4%)	47 (27.6%)	36 (21.1%)	5 (3.0%)						
How able patient felt to share feelings (Q3)							106 (62.2%)	23 (13.5%)	17 (10.0%)	10 (5.9%)	10 (5.9%)	4 (2.5%)

Table 3 Variables compared between patients feeling low and high anxiety

Factor	Mann–Whitney *U*	*p* value	Spearman's rho correlation coefficient	*p* value
Dyspnoea	2,440	0.001	0.299	<0.001
Cough	2,462	0.001	0.256	0.001
Haemoptysis	2,994	0.021	0.189	0.015
Current PS	2,142	<0.001	0.318	<0.001
Low self-esteem	1,625	<0.001	0.515	<0.001
Life not worthwhile	1,874	<0.001	0.427	<0.001
Perception of anxiety within the support network	1,307	<0.001	0.570	<0.001
Survival from diagnosis	390	0.030	−0.274	0.024
Survival from questionnaire	368	0.024	−0.240	0.050
CRP	2,386	0.044	0.119	0.142
Perception that they are able to share feelings	2,931	0.134	0.204	0.009
Pain	2,891	0.139	0.203	0.009
Age	3,111	0.342	−0.148	0.075
Gender	3,156	0.349		
Histology	3,111	0.248		
PS at diagnosis	2,463	0.088	0.108	0.186
Weight at diagnosis	2,726	0.570	0.028	0.532
Current weight	2,827	0.281	−0.05	0.532
Diagnosis albumin	2,640	0.088	−0.137	0.084
Information needs	2,414	0.072	0.152	0.062

Associations of perceived anxiety within the support network

Anxiety perceived by the patient in their support group was categorised as 'lower' (never anxious to sometimes anxious) and 'higher' (most of the time to preoccupied). The analysis was repeated to assess differences between these categories (Table 4).

There was a strong positive correlation between 'anxiety felt' and 'anxiety perceived' (rho 0.570; $p<0.001$). In keeping with this, patients perceived increased anxiety within the support group when symptoms were increased and physical function declined. Perceived increased anxiety within the support network was associated with shorter survival.

Again, low self-esteem and feeling that life was not worthwhile correlated strongly with anxiety perceived in the support group. There were no differences in gender, tumour type, current or diagnosis weight.

There was a significant difference and correlation between information needs and anxiety perceived. This may reflect patients' awareness of the need to have shared information within the support network.

Discussion

Anxiety is a common and normal response to a diagnosis of cancer [32]. It can become maladaptive for some patients, impacting on quality of life, function and symptom burden. Maladaptive anxiety is characterised as being persistent, intrusive and disproportionate to the stimulus. Assessing anxiety within the context of a real and persistent but dynamic threat such as cancer is a challenge [3, 7, 14, 32, 39, 42].

Lung cancer is a serious diagnosis that often heralds high symptom burden, decline in physical health and short survival. Patients diagnosed with lung cancer may not have their supportive care needs fully recognised or met [25–27, 31, 37]. It has been recognised that patients deal with illness in the context of a social environment and that this may positively or negatively influence their ability to cope [18, 21].

The concept of symptom distress, encompassing symptom occurrence, intensity and impact on patients is gaining

Table 4 Variables compared between low and high perceived anxiety

Factor	Mann–Whitney *U*	*p* value	Spearman rho correlation coefficient	*p* value
Dyspnoea	2,345	<0.001	0.281	<0.001
Cough	2,436	0.001	0.27	<0.001
Haemoptysis	2,937	0.009	0.15	0.054
Current PS	2,139	<0.001	0.326	<0.001
Low self-esteem	2,458	0.004	0.295	<0.001
Life not worthwhile	2,715	<0.001	0.190	0.016
Anxiety and worry	1,483	<0.001	0.570	<0.001
Survival from diagnosis	242	0.001	−0.444	<0.001
Survival from questionnaire	229	0.001	−0.434	<0.001
CRP	2,540	0.204	0.610	0.455
Perception that they are able to share feelings	3,162	0.362	0.099	0.205
Pain	2,601	0.013	0.175	0.025
Age	2,607	0.009	−2.227	0.003
Gender	3,174	0.386		
Histology	3117	0.261		
PS at diagnosis	2,508	0.141	0.113	0.168
Weight at diagnosis	2,524	0.182	0.120	0.142
Current weight	2,948	0.471	−0.260	0.746
Albumin	2,090	<0.001	−0.256	0.001
Information needs	2,256	0.007	0.160	0.049

ground [9]. Congruence between patient perception of symptom distress and that of their support network or professional carers may also influence their ability to cope with and discuss their illness [4, 33, 44].

This evaluation confirms that anxiety is a significant issue within the lung cancer population. Fifty-four percent of patients experienced moderate or severe anxiety. Over 20% of these patients felt anxious about their illness 'most of the time' or were 'completely pre-occupied'. This is consistent with findings of moderate to severe anxiety ranging between 10% and 45% in other lung cancer studies [22, 28, 32]. Confirming previous studies, there was a strong correlation between anxiety and depression ('Have you felt your life worthwhile?' and 'have you felt good about yourself?') [8, 28]. It is of note that patients in this study perceived higher levels of anxiety in their support network (mean 2.12, median 3, SD 1.45) than the level of personal anxiety they described (mean 1.51, median 1, SD 1.25).

Patient anxiety is increased in advanced cancer, when symptom burden is high and physical function is poor [7]. We confirmed this and further observed that specific clinical variables of dyspnoea, cough, haemoptysis and decline in performance status were associated with increased anxiety. It is interesting to note that as a patient's own anxiety increases, they also perceive increased anxiety within their own support network. This congruence of psycho-emotional response may influence the support felt by the patient and their willingness to discuss their illness or feelings. It could be hypothesised that patients may feel that support network anxiety which mirrors their own shows recognition and understanding. For other patients, they may wish to withhold their own worries in an attempt to protect their significant others.

The relationship between anxiety and cancer survival is unclear and remains controversial [2]. This study described higher anxiety levels in patients who had shorter overall survival and shorter survival from when the questionnaire was completed.

Within this group of lung cancer patients, the vast majority felt able to share 'as much as they wanted' or 'most of the time' and there was no difference between the group that perceived 'lower' anxiety and 'higher' anxiety in their support network. There was also no difference in this freedom to share between those who were personally experiencing 'lower' levels of anxiety and those experiencing 'higher' levels of anxiety. A minority of patients felt able to share only 'occasionally' or 'not at all with anyone'. Early identification of patients with low levels of perceived support may be important to allow targeted supportive care measures to meet this deficit in a timely fashion. This may help prevent psychosocial distress or aid the treatment of anxiety or other psychological issues.

Limitations of this study

This evaluation was conducted in a single centre and thus may portray a site-specific experience. However, other studies have shown similar prevalence of anxiety and correlations of anxiety to depression, advanced disease, high physical symptoms and poor performance status.

There were more females within the study group than males. This is unusual in lung cancer studies as lung cancer is more prevalent in the male population. This is likely to be explained by the mixed population of recent diagnosis (66.5%) and follow-up patients (33.5%).

Conclusions

Anxiety is an important issue in cancer care. It may reflect recognition of advancing disease or become disproportionate to the current condition. Maladaptive anxiety can 'choke' or 'strangle' the patient's quality of life.

This paper confirms the significant prevalence of anxiety within the lung cancer out-patient population. Patients do perceive recognition within their support network that their condition merits increased concern when symptoms are high, function poor and survival short. The majority of patients felt able to share their worries and concerns with significant others, irrespective of their own anxiety levels.

Lung cancer care operates within a dynamic and often rapidly declining situation. Prompt assessment and response to distress within this acute illness trajectory is necessary. Early recognition of anxiety and facilitating further support—through significant others or members of the health care team—may help relieve the stranglehold of psychological distress.

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